Parents and Professionals' perceptions on the challenges of supporting children with ASD in Greece

By

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Στον πατέρα μου, Στέφανο

To my father, Stefano

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Declaration

The work in this thesis was developed and conducted by the author between January 2015 and December 2018. I declare that, apart from work whose authors are explicitly acknowledged, this thesis and the materials contained in this thesis represent original work undertaken solely by the author. I confirm that this thesis has not been submitted for a degree at another university.

Abstract

This study aims to investigate parents' experiences of raising children with ASD and parent-professional relationships, including teachers, children's psychiatrists, psychologists, social workers, special educators, occupational therapists and speech therapists. Specifically it examined parents' views upon their own well-being and their children's emotional and social functioning. The research was conducted in Greece and focused on the challenges parents and professionals faced as a result of the economic crisis. It also addressed the impact that austerity had upon professional practices and ASD educational provision. The challenging nature of raising children with ASD is key, particularly when parents are faced with poor special education services in terms of the limited special educational provision in schools and constrained resources, as well as the lack of training and the reduced academic accountability of the professionals who work with children with ASD. With the use of 100 questionnaires given to parents and another set of 100 given to professionals who worked in the field of autism followed with 20 interviews with parents and 40 with professionals respectively a mixed methods research design was adopted.

The study is an opportunity for parents' and professionals' views to be heard. It reveals the impact of the austerity policies on children with ASD and their families. It also sheds light on the lack of infrastructure and resources available to parents and professionals respectively. The austerity context intensifies the difficulties that parents and families face in supporting children with ASD and highlighted the need for further training and the importance of effective communication between parents and professionals in order to cater for the needs of ASD children.

Abbreviations

ABA	Applied Behavioural Analysis
AEI	Higher Education Institution
APA	American Psychiatric Association
APHCA	Association for the Health of Psychosocial Children and Adolescents
ASD	Autism Spectrum Disorders
BERA	British Educational Research Association
CYGNET	Psycho –Education Intervention Programme for Parents of Children with Autism
EDEAY	Diagnostic and Evaluation Committee on Educational Support
ETHMA	Specialized Unit for the Treatment of Children with Autism
IEP	Institute of Educational Policy
IEPs	Individual Educational Plans
IKA	Social Insurance Institute
KEDDY	Centres for Differential Diagnosis and Support of Special Educational Needs
KEPA	Disability Certification Centre
KDAP	Centres of Creative Activities for Children
PECS	Picture Exchange Communication System
SEN	Special Educational Needs
SMEAE	School Units for Special Education
SPSS	Statistical Package for Social Sciences
TEACCH	Treatment and Education of Autistic and Related Communication Handicapped Children
TEI	Technological Educational Institute

CHAPTER 1: Introduction

Autism spectrum disorders (ASDs), according to Stampoltzis et al. (2012), are a group of developmental disorders characterized by deficits in socialization, communication, and a restricted repertoire of interests and activities. Stampoltzis et al. (2012) argued that it is a complex lifelong neurodevelopmental condition which continues to raise concerns in the medical, educational and general public domains due to the impact that it has upon the health, wellbeing and quality of life of individuals and their families. This study was conducted in Greece were, I have worked as a SEN school teacher and principle of SEN schools for over twenty years. My experience led me to believe that despite supportive legislation, namely Law 2817 and Law 3699, which were passed by the Greek parliament in 2000 and 2008 respectively and recognized autism as a special need category, there are many issues that still need further investigation (Syriopoulou - Delli, 2010).

In this context, the term special education according to Florian and Linklater (2010), is vague in particular, about how to do the best for the development and learning of children with a disability. The support system in Greece is multi-disciplinary (Sloper 1999), incorporating not only SEN teachers and educators but also a range of medical-related professionals such as physiotherapists, psychologists, and speech and language therapists among others. Effective communication between parents and teachers and other professionals is increasingly viewed as an important factor in the education and treatment of children diagnosed with ASD (Avdi et al., 2000). Avdi et al. (2000) also pointed out that there has been an ideological shift in the area of learning disabilities. 'This shift is reflected in current constructions of the parents of children with learning disabilities as having valuable in-depth knowledge of their child and for that reason are regarded as being central in the implementation of interventions' (p. 327).

Thus far, few empirical studies have been conducted in Greece to examine the impact of contextual factors such as parents' involvement with children's learning, parent – professional co-operation, types of services offered in special education settings, the lack of public services and the generally limited resources devoted to autism spectrum disorder (ASD) children's educational provision. A small number of existing studies, e.g. Papageorgiou and Kalyva, (2010); Konstantareas and Homatidis, (1989); Avramidis and Kalyva, (2006); Mavropoulou, (2007) examined parents' needs but paid scant attention to the nature of the support services available for families with

ASD children or the challenges parents face with regard to the care and education of their children.

However, Penn (2000) demonstrated how education and correspondingly education of the disabled is a highly context specific endeavor. Ravindran and Myers (2012) also claimed that all development, including disability, occurs within a socio-cultural context. With this in mind, Bronfenbrenner's ecological model was the theoretical structure used in this study to examine the interplay between various ecological systems that have an impact on child development.

This study was conducted during a period of austerity in Greece. This meant that many families in Greece faced serious challenges in supporting their children with ASD, principally in terms of overcoming the financial difficulties brought about by the economic crisis, and the lack of appropriate educational provision (Gena, 2006).

Furthermore the researcher's line of work made her realize the challenging nature of raising children with ASD particularly when parents are faced with poor special education services, the limited educational provision in schools and constrained resources.

Within this context, this study aimed to explore the challenges families face in supporting children with ASD in Greece. The focus of the study is the relationships between parents and professionals and the barriers to their attempts to co-operate effectively in the best interests of the child.

This study is founded on the belief that despite the complexity of policy and practice, children with ASD are a group deserving of more focused attention, in particular, because of concern for their social and educational inclusion and development. By examining the views of parents and professionals, this study seeks to stimulate a professional dialogue to discover how to achieve social and pedagogical effectiveness. A closer understanding needs to develop of how the learning and development and education of ASD children can be supported within the family and local community.

By discussing the different values, attitudes, and practices of parents and professionals, this study seeks to contribute a closer understanding of the complexity of the upbringing and education of these children. Using a mixed methods exploratory design, this study attempted to answer the following research questions:

1. What challenges do parents face in supporting their children with ASD in a resource - starved country?

2. What are the parents' and professionals' attitudes to children with ASD's educational and social needs?
3. What factors influence inter-professional and parent - professional collaboration regarding ASD diagnosis and the provision of support?

CHAPTER 2: Literature review

This research has a traditional narrative literature review. A systematic literature review might seem appropriate since it uses a clear set of criteria to identify and appraise all the literature on a particular topic relevant to a pre-defined research question. Systematic reviews aim to find the most reliable research, from methodology to hypotheses, taking account of any confounding variables or modifiers, because the objective is a meta-analysis, of the combined results of various studies as secondary data (Thacker, 1990; Petitti, 2000). Neither the nature of the studies reviewed in the following chapter, nor the research design and methodology followed in this study place it within the parameters of a systematic design as this study does not undertake a meta-analysis. The researcher refers to both qualitative and quantitative studies and used a mixed method research design. Lambert (2012) argued that a literature review is 'a clear and balanced picture of current leading concepts, theories and data relevant to the topic' (Hart, 1998, p. 173). The researcher subscribes to this notion and used the literature review to help frame her study and her work's perspective. The literature review's organization reflects the author's view of the relevance of the study's to her research topic.

2.1 Definition of Autism

The term "autism" originates etymologically from the Greek word "self " and indicates the isolation of a person to himself. Initially, this term was used by the Swiss psychiatrist, Eugen Bleuler, in 1911 to characterize some schizophrenic individuals who had lost contact with reality. Then, in the early 1940s, two other psychiatrists, Leo Kanner and Hans Asperger, described cases of children experiencing deficits in social development, peculiar linguistic development and limited stereotypical interests (Baker, 2013). According to American Psychiatric Association (APA), Autism Spectrum disorder is a pervasive development disorder, with a complex clinical diagnosis without known biomarkers or clear etiology (APA, 2013).

Autism falls into the category of Developmental Disorders. These disorders are characterized by severe deficits in many areas of development at the same time. In addition to autism, Asperger disorder, Rett disorder, child disorder, and developmental disorder not otherwise specified are included in the category of Developmental

Disorders. The Asperger disorder describes children who present the same symptoms as children with autism, but without the language development deficits. The Rett Disorder characterizes children who begin to experience specific deficits after a short period of normal development. Children's disruptive disorder characterizes children who experience a general regression in many areas of development after a period of normal development. Unspecified developmental disorder otherwise characterizes children who have severe developmental deficits but do not fully meet the criteria for any of the above categories (Fombonne, 2003).

People who experience autism have the following characteristics:

- Social skills deficiencies (human voice does not cause interest, difficulty in forming emotional relationships even with parents, lack of eye contact, gestures and other skills, non-verbal communication, no social smiling or ability to imitate, no understanding of emotions).
- Communication difficulties - unusual language development (lack of speech or limited speech development, echoes the sounds other's make, uses "you" instead of "I" when referring to the self, stressful behaviour and poor voice quality).
- Stereotypical behaviour (routine behaviour such as swinging, swirling, tapping the fingertips, fast finger movements in front of the eyes, constantly arranging toys, insisting on the same sequence for performing certain activities of everyday life, memorizing elements of a specific subject).
- Delay in cognitive development (76-89% of children with ASD have mental retardation, IQ <70) (Gabriels and Hill, 2010).

In several cases, related problems are also reported in people with autism. Many autistic people show self-harming behaviour (hair pulling, head banging, hand biting). Parents also report eating and sleep disorders, as well as the occurrence of intense phobic reactions to everyday objects. There are also signs of hyperactivity and attention deficit disorders (Gabriels and Hill, 2010).

2.1.1 Autism types

Autistic Spectrum Disorders include different syndromes with the most important listed below:

- Asperger's syndrome deficits focus on social transactions and stereotyped behaviours. The main difference between Asperger's syndrome and other forms of autism is that the majority of people who have it have no lag (or cognitive developmental delays), and their linguistic development and cognitive functions are normal. Although their intelligence is generally characterized as normal, people with Asperger's syndrome tend to be clumsy. The condition remains unchanged during adulthood unless psychotic episodes appear, something that happens in some cases, although the syndrome is generally considered to be a milder form of autistic disorder, according to current evidence (Myles, 2005).
- Rett Syndrome is very rare and mostly affects girls. While in the first six months or so, the child appears to have normal development, but when she gradually begins to use her hands, she is unable to hold or handle objects. In addition, she begins to make specific, stereotypical movements with her hands, such as rubbing them together or clapping. The next problem is the development of the head, which may be slow or completely stop. Co-ordination problems and muscle control are also acute for walking, and the use of a wheelchair in the future is inevitable. Other problems such as spinal curvature, excessive inhalation and air ingestion, and teeth grinding may occur. All these problems appear to lead to social exclusion for the child. She also has learning difficulties, her speech is absent or limited, and she is unable to play pretending games like other children. The big difference between this syndrome and other types of autism is that at some undetermined point, the autistic problems disappear and the child is able to socialize but the physical problems remain. The reasons for this change have not been established, nether have the causes of the syndrome (Kaufmann et al., 2010).
- Landau-Kleffner syndrome manifests itself after the critical age of three years, by which time the symptoms of autism have usually occurred, and up to the age of seven. The child develops normally up to age three, although in some cases, there can be problems in the development of speech. Gradually, however, the child begins to avoid direct eye contact, presents language problems, makes repetitive movements, and rejects any form of change. If the child is subject to an encephalogram, the result will not be normal, but if the syndrome is suspected, specific techniques should be carried out first (Robinson et al., 2001; Smith and Hoeppner, 2003; Mikati and Shamseddine, 2005).

- Cornelia de Lange's Syndrome: The main feature of this syndrome is the frequency of the child's self-harming (Moss et al., 2008).

2.1.2 ASD Theories

To better understand this disorder requires more than knowing the clinical picture, but must take into account the underlying cognitive deficits that characterize it. This can be done through the theory of mind, i.e. the ability to attribute mental states like beliefs, intentions, pretense, and desires both to oneself and to others.

The central deficiency in autism is considered to be their limited or incomplete concept of mind, i.e. they lack the intuitive ability to realize that others do not automatically know the feelings and desires they experience themselves, or that others have feelings and thoughts that differ from their own, which the average child is capable of from the age of about four years. This lack in their theory of the mind may explain some of the communication difficulties people with ASD suffer from (Baron - Cohen, 2000; Pellicano, 2007).

Another major cognitive deficit is weak central cohesion. People with autism have a particular cognitive style of information processing that favors fragmented rather than holistic processing. They seem to process information and situations by focusing on details. Thus, several people with autism demonstrate skills in specific activities and tasks such as puzzles, remembering phone numbers, car number plate after only a brief glance, and so on (Burnette et al., 2005; Pellicano et al., 2006; Pellicano, 2010).

2.2 Autism in the Greek educational context

A plethora of research in the field of special educational needs (e.g. Gray, 2003; Hutton and Caron, 2005; Montes and Halterman, 2007; Tomanik, Harris, and Hawkins, 2004) has discussed the difficulties that parents of children with ASD often face in their daily lives. Glover-Graf (2011), for instance, claimed that parents of children with ASD are likely to experience strained marital and extended family relationships, social isolation, challenging educational arrangements, and a sense of grief related to the restricted opportunities for their children. In this regard, a diagnosis of ASD affects not only the diagnosed individual but extends to the entire family. In fact, parental participation in terms of their ability to advocate effectively on behalf of their children

entails the presumption that parents will be able to identify their needs, recognize their strengths, challenge practices, to negotiate in decision making, and are willing to express dissent to providers, as well as reach a resolution to all these issues.

Given that parents are often seen as the most influential agents for children with ASD (Wang, 2008; Singer et al., 2012), some researchers (i.e. Beckman, 2002; Prelock et al., 2003; Beatson, 2008) have stressed the importance of providing family-centred care by taking into account the ongoing interaction between families and professionals. Prompted by the increase in the prevalence of ASD, autism was recognized as a special needs category under educational laws numbers 1566 and 2817, enacted by the Greek parliament in 1985 and 2000 respectively. In 2008, a new educational law (number 3699) was introduced, specifying that educational placements for children with autism should be determined according to their cognitive, language and social development (Syriopoulou - Delli, 2010). However, even though this shows that the government is aware of the needs of ASD children, there are no comprehensive official statistics on the exact number of Greek people with ASD (Centre for Education Research, 2009)

With regard to previous empirical studies that have explored the needs of children with ASD in Greece, almost all of them (e.g. Gena, 2006; Hitoglou et al., 2010; Kalyva, 2013; Makrygianni and Reed, 2010; Stampoltzis et al. 2012) were quantitative studies, and examined the difficulties that Greek parents of autistic children encountered without seeking to suggest practical steps to overcome their difficulties and failed to explore the working relationship between parents and professionals.

However, the findings of studies carried out by Kalyva (2013) and Stampoltzis et al. (2012) showed that there was a noticeable lack of services offered to autistic children in Greece, especially in terms of the quality of education and care. They argued that the Greek government did not offer sufficient financial support to parents of children with ASD or to professionals in the form of training and professional development. It is noteworthy that very few secondary schools in Greece were found to be appropriate for ASD children in terms of the curriculum content and appropriate teaching methods or adequately trained staff (Kalyva, 2013; Stampoltzis et al., 2012).

Parents of children with ASD in Greece, as suggested by Kalyva (2013), tend to be discontent with the facilities given to their children in formal educational settings (special needs schools). This is, in general, ascribed to the lack of experience of most mental health professionals outside the school settings in dealing with the symptomatology of autism.

Increasingly, many families in Greece face serious challenges in supporting their children with ASD, principally in terms of overcoming the current financial difficulties due to the economic crisis in Greece, which affects the employment of many, and coping with the lack of appropriate educational provision (Gena et al., 2006). Thus far, few empirical studies have been conducted in Greece to examine the impact of contextual factors such as parents' involvement with children's learning, parent – professional co-operation, types of service offered in special education settings, the lack of public services and the generally limited resources for the education of children with ASD. A small number of studies (e.g. Avramidis and Kalyva, 2007; Konstantareas and Homatidis, 1989; Mavropoulou, 2007; Papageorgiou and Kalyva, 2010) have examined parents' needs but paid scant attention to the nature of the support services available for families with children with ASD or the challenges parents face getting the care and education their children need.The diagnosis of autism requires a multi-disciplinary team to diagnose the appropriate support and special educational needs(K.E.D.D.Y) of particular children. The diagnosis helps a child with ASD achieve his/her potential with special educational support and guide the parents of children with autism in how to encourage their child to fulfil his/her potential.

2.2.1 Law 3699/2008

In recent years in Greece, following the formulation of the appropriate legal framework (Law 2817/2000 and Law 3699/2008), children with learning disabilities have been given the opportunity to integrate into mainstream education.

Support for these students in mainstream education is done in three ways. The first is the cooperation of the mainstream class teacher and the specialist teacher in the context of the integration function. The second way is to support only the mainstream class teacher if there are no special education services in the school unit. The third way is the cooperation of the teacher of the mainstream class and the special teacher in the context of inclusion (Law 3699/2008).

The concept of inclusion or otherwise parallel support in class is based on the right to equal education of all pupils but in Greece, at least, the criticism it has received is quite intense because the parents of mainstream pupils feel it will damage their education as they will not be sufficiently challenged, too much attention will be paid to ASD children, who will be disruptive. However, it cannot be denied that the inclusion

of children with special educational needs within mainstream is their inalienable right and should be ensured. In order to achieve this, they need access to mainstream education with approaches that can meet their needs.

The inclusion of children with autism is not just a matter of help from a trained person or about receiving support; it also depends on the quality of service or support offered. Comprehensive education should include the reorganization of the curriculum and the organization of the class to meet all needs, which distinguishes it from integration that focuses on an individual person, whose needs have to be adapted to what schools have to offer.

The most recent Law 3699/2008 (No. 2) on the organization and objectives of Special Needs Education refers to the integration of pupils into the education system, social life and occupational activities as well as to mutual acceptance, harmonious coexistence within the social community and equal social development, all these aimed at ensuring full accessibility for all pupils, including those with disabilities, teachers and/or their parents and guardians, to all social services (Alevriadou and Lang, 2011; Stamou et al., 2016).

In Greece, inclusive education gained an institutional imprint with Law 3699/2008 where cooperation between general and special education teachers is referred to so that the learner with special needs can receive the best possible support. The same law has the first reference to the inclusion of all students in the same class, while providing appropriate support for those with learning disabilities.

Law 3699/2008 amended the previous legal framework in the area of special education by focusing on inclusion. For this important project to be successful in Greece requires the appropriate basis and support for long-term development. Of necessity, account must be taken of all the particulars present in the life of a child with special learning needs. For the effective operation of this law and for steady development, the cooperation of all the actors in the education system, legislature, education policy makers, teachers as well as students themselves, is required.

Inclusive education not only has an educational, but also a social dimension. The new law attempts to establish this through the Greek curricula and in general in education, aiming to provide pupils with special learning needs with the necessary training to help them integrate smoothly into society, and are provided with what the other students enjoy.

2.2.2 Parallel support and inclusive education

In recent years, the method of co-teaching for children with special educational needs has been increasingly gaining ground in the world. The focus of this method was considered to be particularly effective in dealing with children with special educational needs in inclusive education, i.e. being taught along with other students (Scruggs et al., 2007). The coexistence of two teachers in the same class is collaborative teaching and is a very good opportunity for teachers to develop their skills. By their combined existence in the classroom, they can provide new knowledge to each other, since one teacher knows the needs and objectives of the curriculum that concerns all students while the other educator knows the needs and approaches required for students with specific learning needs. In this context, both teachers in co-operation can provide pupils with knowledge and at the same time, strengthen their mutual tolerance and acceptable social behaviour (Connor et al., 2006; Sileo and Garderen, 2010).

This means that by investing in both the academic and social behavioural fields, children with special learning needs can share social, educational and geographical space with other students without being treated in a way that marginalizes them from the social context of the classroom and the educational unit in general (DeFrance Schmidt, 2008).

The field of inclusive education involves specialists, many of whom consider that the term Special Education should be replaced by Inclusive Education. Many researchers react to this by addressing the weaknesses in education systems. They believe that the proposed inclusive education does not work positively and that there is a risk that it will negatively affect all previous improvements in all other areas of education (De Boer et al., 2011).

In 2010, an international conference was organized by the Spanish Ministry of Education under the aegis of the Spanish Presidency of the European Union, with the title ‘Inclusive Education: A Way to Promote Social Cohesion’. The impetus came from UNESCO and the European Agency for Development in Special Education Inclusive Education in Action (IEA, 2010). It is a program aimed at providing information to policy makers to help them design and implement important policies through examples that clearly illustrate the actions outlined in the UNESCO Policy Guidelines on Inclusive Education.

This congress was a noteworthy example of the practical implementation of proposed actions in line with the UNESCO Policy Guidelines on Inclusive Education.

The main formulation focuses on producing innovative programs and galvanising the support and ability of society to children with ASD, young people and adults outside the school context with a view to integrating them into school, education and training programs. In addition, policies that reflect the rights-based opportunities and defend the weaker are proposed in the Guidelines. Thus, these policies should target underprivileged children, with information campaigns through the media, posters, conferences, and especially, education (UNESCO, 2010).

The Madrid conference, involving representatives from the different Autonomous Communities of Spain, other European countries and Latin America, as well as volunteers, with the aim of encouraging education policies that promote equality, social cohesion and active citizenship. The urgent need to solve problems, such as early school leaving and the need for additional educational support for problem students, were identified.

This conference also claimed that very good policy, theoretical and practical progress has been made to support the process and the evolution of the Inclusive practice in Special Needs Education. The conference concluded that the United Nations Convention on the Rights of Persons with Disabilities, in particular Article 24, on education, should be adopted and that it was necessary to overcome any shortcomings in order to achieve these objectives to achieve the goals of quality, equality, integration, respect for diversity and effective participation within a society that does not allow for exclusion in education.

One of the proposals that emerged from this conference was the active participation of pupils in decisions on any subject that directly concerns not only their education but also their future as citizens (IEA, 2010).

At this point, the problems identified or likely to occur during the inclusion process need to be considered. Children with difficulties who are entering primary school after early years education have to adapt to a new environment, build relationships with their peers, and acquire new knowledge and skills. The transition process has to be very well organized because a child with difficulties in a new environment may experience stress, insecurity and uncertainty. In order to achieve a smooth transition to the new environment, certain factors need to be co-ordinated, that is, education programs should be carefully planned, with coordination and cooperation between teachers. A very important factor for inclusive education to work well is for the child and his/ her own family to prepare for the new environment during pre-school

education, in order to acquire the necessary skills to enable them to attend the first grade of elementary school. Another important factor is agreement between preschool educators and teachers on identifying the necessary skills for a smooth transition from one school environment to another (McKenzie, 2009).

In order to avoid problems that may arise during the inclusion of pupils with special educational needs with the other students, educational and advisory interventions, designed and implemented within the school, will play a decisive role, although positive results may not be achieved immediately, but through cooperation and experience.

The educational interventions primarily have to do with the individual curriculum of each student, which will be combined with studies in the regular classroom, and consulting interventions involving the student, her family, and all other members of the school unit. Children with special educational needs need specialist help and counselling throughout their schooling. For the smooth attendance of these children, Special Needs Teachers in addition to their specific subject knowledge, need high level communication and counselling skills.

Argyropoulou and Papoudi (2012) attempted to document the theoretical context of inclusive education in Greece through a case study. The research showed that there can be significant improvements, particularly in the area of an autistic child's communication with the rest of the class. However, the researchers note that the educator should use interventions in such a way that the child with autism is motivated to develop her communication. In another study, Kossyvaki and Papoudi (2016) examined the role of play to support the cognitive development of the child with ASD.

The pedagogy of inclusive education has been widely explored by the academic community (Avramides and Norwick, 2002; Hehir and Katzman, 2012). Some researchers favour of inclusive education (Avramidis and Norwick, 2002; D'Alonzo et al., 2010), but many hold negative views of how to implement it (Hornby, 1999; Kauffman, 1999). Teachers' views of inclusive education have also been studied (Zoniou-Sideri and Vlachou, 2006; Racap and Kaczmarek, 2010).

Some surveys show negative tendencies in teachers' views on inclusive education, such as Racap and Kaczmarek's (2010), which showed that most teachers surveyed had negative attitudes about the inclusion of people with special educational needs. Similar findings have been recorded in other countries, such as Serbia (Kalyva et al., 2007), also in Israel and Palestine - with reservations about specific forms of

disability (Lifshitz et al., 2004). Teachers' attitudes to inclusive education vary, depending on the type of disability of their students, their previous experience and contact with pupils with special educational needs, their training, the position and the level at which they provide education, as well as the availability of resources, the support they themselves receive and their cooperation with other stakeholders (Avramidis and Norwich, 2002).

2.3 Raising a child with ASD

2.3.1 Children with ASD in family and wider social contexts

The family has the strongest and most long-lasting impact on the life of a child with disabilities and special needs. Within the family he/she grows, learns and all their needs are met. Taking care of a disabled child may bring mental and emotional rewards but also involves responsibility, obligations, fatigue and anxiety (Lustig, 2002).

People with disabilities have more demands and needs at both a physical and emotional level in their day-to-day activities. The parents of people with disabilities, in addition to their obligations of bringing up a child, also have to deal with other situations, which are often unpredictable. They need to adapt to their child's chronic condition, both on a practical level by making changes to their lifestyle, roles, schedules, and emotional responses, by overcoming initial feelings of sadness, shock and guilt and by changing their expectations and dreams (Lustig, 2002).

The individual lives and grows within the family, but the family also evolves and interacts with other systems - the neighbourhood, the local community, etc. Bronfenbrenner was one of the first to define the development of the individual and the family within a social ecological context. He used the term ecological development to describe the process of mutually progressive adaptation between the evolving human organism and the rapidly changing environments in which it lives during its life.

Bronfenbrenner's ecological system consists of five socially organized subsystems that help, support and guide human development (Bronfenbrenner, 1994) and structures that are connected, each being integrated within the other. The innermost structure is the microsystem that is the model of the activities, social roles and interpersonal relationships that the developing person experiences. In the microsystem, interactions take place face to face and with specific symbolic, physical and social features that allow the participation of the individuals in increasingly complex

interactions. Examples of microsystems are the family, school, peer group, etc. (Bronfenbrenner, 1994).

The subsystem that includes the interfaces and processes that take place between the microsystems includes the developing individuals. For example, one subsystem is the relationship between the school and the family, made up of two different microsystems in relation to the development of the child (Bronfenbrenner, 1994).

Extra systems, in turn, also have interfaces and processes that take place between microsystems. The problem, however, is that in this structure there is a microsystem that does not directly affect the child's development, but within the microsystem else, other events can occur that affect it. For example, an extrasystem is the relationship between a child's home and his father's work. Although the child does not participate in her father's work, what happens to him can indirectly influence her development (Bronfenbrenner, 1994). If her father, for example, is experiencing bad conditions and problems at work, then he may not be able to engage in activities involving his child, similarly for the child's mother. Also, the loss of the father's job can bring another other micro-system to which the home is connected and put it in a bad position (financial difficulties, psychological problems, tension in family relationships, etc.) and influence the development of the child (stopping the child's activities due to financial weakness, indifference to the child and her activities, etc.).

The macro system consists of the main models of previous systems within a culture or cultural group (Bronfenbrenner, 1994). These are values, beliefs, practices, knowledgeable bodies, material resources, customs, lifestyle, dangers, and so on which are shared by the members of the cultural group and transferred to the newest members of the group. Cultural groups are distinguished not only because of their existence within different societies but also as groups that exist in particular societies due to the differences that may exist in region, race, ethnicity and socio-economic situation (Tudge et al., 2000). Of course, such standards are not simply reproduced by members of a cultural or social group but are also shaped and modified by them. Thus, parenting practices, for example, are not uniquely defined by factors such as social class but are identified by the parents themselves according to the choices they make and the decisions they make on the basis of their knowledge, opinions and experiences (Tudge et al., 2000).

Finally, another system used by Bronfenbrenner extends the environment to a third dimension. Traditionally, in the study of human development, the passing of time

has been seen as synonymous with chronological age. But here, time is also seen as a property of the development environment. The time system therefore includes changes or consistency, the characteristics of the person over the passage of time and the environment in which this person lives, such as changes in the family structure, socio-economic situation, etc. (Bronfenbrenner, 1994).

For Bronfenbrenner, day-to-day activities are essentially 'the engines of development'. When people participate in them, they understand what is expected of them, what activities are considered right and proper, and what not, what is the expected way to deal with them. They also understand the way they interact and the kinds of interaction to have with other people. Through these processes, children may experience them in the same way, but they children also benefit from their observation of other social roles (Tudge et al., 2006).

This highlights the great importance of activities both for learning and for the development of children. The social and cultural context in which they live and grow, sets, due to its system of values, specific rules and standards for their development. Everyday activities are in fact a " guide" for children, because within them and with the interaction they create with others, both children and adults, they understand what they are expected to do, the ways in which they have to act, and what their contacts and relationships with others should be. As examples of these contacts and the interactions they create, Bronfenbrenner mentioned the parent-child relationship and the child-child relationship within activities, and so on (Tudge et al., 2000). For example, in the parent-child relationship, the parent usually indicates how the child should be involved in activities and how they should be conducted. The same applies to the child-child relationship; one assumes the role of leader, in essence.

In conclusion, Bronfenbrenner's development theory focuses on the PPCT/Process-Person-Context-Time (Activity-Person-Context-Time) model. Activity is the most important concept. Development is achieved through activities and is accomplished by the interaction between the individual and others, the objects and the symbols that exist in her immediate environment. In the case of children, this includes their parents, the child's activities in play groups, etc. The child's immediate activities are the focus of his daily activities, during which the child is involved with other children, which is part of his development. The involvement and interaction of the child with other people during these activities, especially those that have developed greater skills, helps the child to understand what is considered acceptable and what is not in the

cultural context that she lives in and is an important factor for development (Tudge et al., 2000).

According to Bronfenbrenner, the developing person is not only treated as an individual unit but as a bio-psycho-social being, influencing in its own way, the systems that control its behaviour. The focus of interest is shifting to functions within the system rather than intra-individual procedures. It makes no sense to isolate the individual but to study his or her in relation his/her direct or indirect social environment (Petrogiannis, 2010).

The value of the ecosymbolic approach is that it gives meanings and ways in which the effects of the framework and the operational effects of the environment can be assessed (Simeonsson and Boyles, 2001). Therefore, it can be understood how the functioning of a child with ASD is affected but also how she affects the social systems with which she comes into contact, such as family, educational framework and professionals. The ecological theory Bronfenbrenner (1977) can be beneficial in explaining the family dynamic of families who have a child with ASD. The theory maintains that the environment affects the development of the child and there is reciprocity with regard to this process. It also focuses on the importance of changes over time with regard to an individual's development (Bronfenbrenner, 1979). The interaction of structures within a layer and interactions of structures between layers is key to this theory. Children with ASD do not have the constant and mutual interaction with important adults (parents, careers) that is necessary for their development. Since the relationship between a child with ASD and the immediate micro system of the family appears to be difficult the child does not have the tools to explore different parts of his/her environment. The relationships that children encounter among major settings outside of the immediate family is another area of focus for the ecological theory. The way the child's home life interacts with other familiar settings such as schools and peers or other more remote environments affect the child's mesosystem. People who are close to, or work with children with autism should seek to understand, construct, and control the transactions among those environments for the ultimate benefit of persons with autism and their families. Due to their atypical development children with ASD miss out on typical activities with peers. They cannot interact effectively with other social groups such as school and friends. Their condition influences all aspects of family life and makes the rest of the family members experience feelings of isolation and embarrassment.

2.3.2 The importance of ASD for parents

Living with a child diagnosed with ASD poses unique challenges for parents who are often themselves at risk of developing negative psychological outcomes, including high levels of stress (Ingersoll and Hambrick, 2011; Griffith et al., 2010; Ludlow et al., 2012). These challenges are often the result of the mismatch between parents' needs and the resources available. This could be addressed most effectively when policy makers and service providers collaborate with families to identify the needs of parents and to establish family - centered policies and services that meet their needs as well as those of their children (Prelock and Hutchins, 2008; Resch et al., 2010). A significant amount of research conducted in the international context indicates that raising a child or adult with a developmental disability demands exceptional levels of care-giving and contributes to higher levels of stress (Dyson, 1997; Hassal et al., 2006; Hayes and Watson, 2012; Myers et al., 2009; Ludlow et al., 2012; Whitaker, 2002). Caring for a child diagnosed with an autism spectrum disorder (ASD) has been shown to be especially stressful for carers, due to the complexity of symptoms that characterize this disability (Ingersoll and Hambrick, 2011; Griffith et al., 2010; Konstantareas, 2009; Woodgate et al., 2008).

Parental hopes for a typical child may explain their psychological process of mourning and constant stress resulting from caring for a child with ASD within the family. A child who does not communicate with other family members is unable to join the family web. Instead, family members have to adapt to the reality created by the existence of this child, especially if their behaviour is disruptive. In this environment, stress can be high for parents and siblings, and it is reasonable to assume that the more difficult the child's behaviour is, the higher the levels of stress, especially for the parent who takes most responsibility for her care (Hayes and Watson, 2012).

The psychological and physical endurance of parents can be severely affected if there is no help for the family and the child from mental health and social care services. The lack of services, especially for the preschool child with autism, burdens the family many times beyond its capabilities (Hoogsteen, 2011). Many families with a child with autism live in constant high stress levels with one parent, usually a mother, working non-stop. Under these circumstances, it is not uncommon for some parents to feel alone and helpless and develop post-traumatic stress syndrome, which, without treatment and

care, also becomes part of their daily life (Estes et al., 2009; Rao and Beidel, 2009; Hayes and Watson, 2012).

The above arguments are supported by a series of research findings. A seminal study in Greece is that by Konstantareas and Homatidis (1989). Their survey sample was the parents of 44 preschool children with ASD. The survey showed that parents were not able to understand the implications of children's symptoms and that their primary anxiety factor was the possibility the child injuring herself.

Much previous research in the area of parent caregiver wellbeing has focused on the challenges caused by the child's behaviour, and the severity of the disability (i.e. Plant and Sanders, 2007) rather than the lack of the necessary environmental support (Resch et al., 2010). Regarding this support, the number of children diagnosed with ASD continues to rise, yet there are in-sufficient resources available to support parents and families (Hall and Graff, 2011).

2.3.3 Implications for families

Taking care of a child with autism is not easy for families, as pointed out, and the serious problems the autistic child's family has to face have a negative psychological impact on their members, particularly on the mother of the child. A number of studies have documented the adverse psychological impact and burden on the autistic child's family.

A key concern that the autistic child's family has to manage is the dangers the child faces and the ways they can use to protect her in combination with the other difficulties, parents are burdened with, both psychologically and physically. Mothers are more prone to take on the burden because, traditionally, they are usually closer to autistic children and are engaged in raising them on a daily basis, and this makes them particularly distressed about how to deal with all the difficulties (Santoso et al., 2015).

Another research project found that mothers of autistic children are particularly psychologically burdened by the intense anxiety they experience (Griffith et al., 2015) mainly due to the provocative behaviour of the children. Of course, provocative behaviour can also exist in children who do not suffer from autism, especially during adolescence (Smith et al., 2014).

However, high anxiety has been found in mothers with children with ASD who have been helped by the services and where their children have received therapeutic interventions (Rutstein, 2014). Another study also found depression in parents who take

care of autistic children, especially mothers, as a result of the psychological burden of care (Brown, 2014). These findings are also consistent with Bashir et al.'s research (2014) that found that depression in mothers was caused by the despair they feel and the contradictory feelings they experience from the care of their child.

The above findings seem understandable given the challenges mothers face every day. Fairthorne et al. (2014) found that mothers were confronted with a series of challenges that are not found in a typical child's upbringing. The needs of their children have a significant impact on their quality of life as they have to change their lifestyle, giving priority to their child's care, and struggle daily to advocate for their child and in many cases, also face bullying. In addition to anxiety, these challenges create a grief similar to what they would experience in the event of death, since they actually feel that the child they thought they would have has died. In addition, they often face the denial and rejection from their family members and, in some cases, from the father who cannot accept the condition of his child. According to Kwok et al. (2014) research, the mother has the additional burden of her partner's response to his child with ASD's care needs.

In the study of the burden of mothers with children with ASD, individual dimensions have also emerged that aggravate the situation. For example, if mothers have children who injure themselves, display aggression and are older, their level of anxiety increases (Kotsopoulos, 2014).

García-López et al.'s (2016), study of 76 couples, the parents of children with ASD, aged 3-18, found that mothers had higher stress rates than fathers. Fathers expressed a positive perception of their contribution to raising their child, which positively affected their personal development and maturity, which may have reduced their stress levels. However, other studies found no significant difference in stress levels between fathers and mothers, as in the Hastings and Johnson (2001) study which investigated stress using a person-centered questionnaire rather than one on the child with ASD. Their sample was 18 pairs, and according to the results, there was little difference in stress between mothers and fathers, with mothers, however, showing higher scores for the most serious symptoms. Mothers' stress seems to be more related to the child as they often have sole responsibility for caring for and raising them.

2.4 Factors associated with parents' feelings

Hoogsteen (2011) argued that what makes things worse for the parents of children with ASD is the lack of services to support them. This forces them to rely on their own resources to cope with the needs of their children and to struggle continuously to achieve things that other parents consider as given.

Another key factor influencing parents' behaviour is society's ignorance about autism, since their information comes mainly from the mass media, which tends to present a one-dimensional image of a person with autism (Hoogsteen, 2011; Holton, 2014; Tang and Bie, 2016).

This has led to the stigmatization of children with ASD and their families, which has been documented in many surveys (Bolte et al., 2013; Milačić-Vidojević et al., 2014; Dehnavi et al., 2011; La Valle, 2013). The term stigma is used in the sense of the disapproval and exclusion of a person from a social group when it does not match its rules. The stigma and the negative behaviour that accompanies it may come mainly from the prejudices of a social group. Bias is behaviour that is based on information guided by a particular group and concerns another group. That is, someone belonging to a particular group that is separate from the others by a feature that is a principal of that group is evaluated negatively in advance. The emotions that accompany bias are homogenized, having a common negative factor. Prejudice can also be expressed in different forms. It can be manifested through a scornful statement, a humiliating joke, an offensive act, physical assault, unequal treatment at work, by ignoring the needs of others, etc. (Link and Phelan, 2001).

Goffman (1963) argued that people treat stigmatized individuals not only as abnormal, but even as non-human. In the best of cases, the stigmatized is considered a person but incomplete. This categorization is not at all accidental; in many cases, being stigmatised by the 'normal' is their effort to justify the phobias and the hostility they see directed towards these people (Russel and Norwich, 2012).

The stigmatization of children with ASD and the role of parents has been confirmed by research findings. According to Mak and Kwok (2010), the family environment is an important factor in eliminating stigma. According to Green (2003), parents who experience stigma because of their children do not easily allow them to interact with other people for fear of negative reactions to them. It is also important to note that mothers tend to absorb the effects of stigma (Gray, 2002) to a greater extent than fathers. Kinnear et al.'s research (2016) found that the behaviour of children with ASD plays an important role in triggering stigma. Parents who experience stigma due to

their child's condition have been motivated to increase their efforts to take better care of their children (Loukisas and Papoudi, 2016).

Grandparents can also act as carers and helpers, both through their interactions with the child and through their support (emotional, psychological and material) to their parents by reducing their weights (Fewell et al., 1986). A study based on the criticism of the mothers of children with disabilities regarding the support they received from the parents of both spouses showed that grandmothers were more supportive than grandparents, mothers parents offered more help and more knowledge of the child's condition, the support was more emotional, and as the distance grew, the support was diminished (Seligman et al., 1997). Different results emerged from another survey where it seemed that the help offered by the parents to both spouses was scarce, half the parents felt they would like more support, and a 24% reported that their grandparents and their grandparents additional problems (Hornby and Ashworth, 1994). It seems that grandparents can act as support bodies and on the other hand as an additional burden for the family, especially when they have long-lasting negative reactions to the child's disability or when they do not understand their situation and needs.

2.4.1 Inter - Professional collaboration

Inter-professional as well as parent–professional collaboration is a critical issue in the field of special education (Lake and Billingsley, 2000; Blue-Banning et al., 2004). Inter-professional collaboration in the therapeutic health team is a scientifically designed, equitable, cooperative and interlinking effort to achieve a goal that requires interdependent knowledge, experience and the services of different scientific cognitive personnel (Antoniou et al., 2003). Collaboration is a process of working with others, with commonly accepted goals and philosophy. At the same time, it is necessary to understand the particular characteristics of each person in the contracting party - such as their abilities and knowledge, as well as their personality and elements of their behaviour; to know them not just - as a practitioner but also as an individual (Wheeler et al., 2007). Collaboration aims to fulfill a planned purpose, while allowing individuals to still use their initiative. In addition, harmonious cooperation creates a favorable climate where even latent personal potential is expressed and developed, while cultivating and integrating the personality of the collaborators as a group (Avallone and Gibbon, 1998).

Inter-professional cooperation includes communication, guidance in the sense of counselling, observance of common elements, reassessment of data, exchange of information and ideas (Samuelsson et al., 1998). In the field of health care, inter-professional cooperation has become a subject of concern, including to healthcare professionals, as healthcare provision in modern societies is becoming increasingly complex, with many people in different professions being obliged to work together to provide adequate and high-quality health care. In other words, the attainment of high-quality care depends heavily on the ability of health and welfare professionals to collaborate and contribute their specialized knowledge to meet the needs of patients (Hall and Weaver, 2001; Collins, 2005).

Professionals define cooperation as a relationship characterized by the exchange of views about an ASD child, in this case, shared decision-making, mutual trust and respect, the desire to resolve disagreements, frequent contact and discussion of matters on equal terms. That is, none of the parties can claim to be the expert (Burrell and Borrego, 2012). Summers et al. (2005) pointed out that collaboration between professionals (i.e. teachers, educators, service providers) and the parents of ASD children is emphasized in the field of special education (e.g. Lake and Billingsley 2000; Stoner et al., 2005; Strogilos et al., 2011) as a response to the increasing prevalence of the ASD disorder.

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In the US, in 1997, the US Congress passed one of the most important amendments to the Individuals with Disabilities Education Act (IDEA, 2004). This amendment to IDEA, referring to children with disabilities, called for special attention to be paid to the potential of maximizing the interaction between professionals and the parents of children with ASD (Tucker and Schwartz, 2013).

Parental involvement, which is mainly parent-professional interaction, has been established as the key to building a positive educational experience for children with

ASD. Although in many countries, significant efforts are made to involve parents in their children's education (McConachie, and Diggle, 2007; Keenan et al., 2010), it appears that this is not happening in Greece, to any great extent (Gonela, 2008; Kalyva, 2011) and consequently it remains a challenging and interesting topic for academic research and practical development. A review of the studies probing the factors that influence parental involvement in supporting children with disabilities/ASD and their collaboration with professionals, has revealed that there are many potential barriers: a) logistical problems, b) communication problems, and c) lack of understanding (Johnson et al., 2004; Nowell and Salem, 2007). Further to this, Hartas (2004) concluded that there are functional and structural barriers that can prove difficult and ultimately lead to or reinforce professional alienation (e.g. time-commitment/constraints and rigid organizational structures).

Some empirical studies (e.g. Ravet, 2012) indicated that both parents and professionals have built strong relationships based on trust, respect and shared visions that have led to increased communication and appropriate service provision for children with ASD. For instance, researchers such as Lubetsky (2011) suggested that creating successful and effective cooperative relationships between parents and professionals might not be easily achieved. For example, in the context of family-centered early intervention (a philosophy of care and a set of practices), cooperation often remains a utopian ideal. Although professionals appear to favour cooperative relationships with parents, some research (e.g. Bruder, 2000; Epley et al., 2011; Turnbull et al., 2011) has revealed a significant gap between theory and practice due to the fact that that few trusting and empowering relationships can be established between parents and professionals.

In Greece, the context of this research study has been influenced by the serious financial and economic crisis, which has left a mark on the social services provided to children with ASD. Moreover, the reduced economic capacities that now prevail, post-crisis, at both state and family levels, continue to prevent these children from fully enjoying their constitutional right to inclusive education, access to quality health services and effective social care support structures (Policy Department C, 2013). A number of scholars have described social services as being unavailable, difficult to obtain, inappropriate as well as inaccessible (Syriopoulou – Delli et al., 2012). Addressing this, the Committee on the Rights of the Child in Greece recommended investment should be made in the protection of the rights of children in situations where

they are vulnerable, including those of children with disabilities, inter alia, by defining strategic budgetary lines that must be protected even in situations of economic crisis (Policy Department C, 2013).

It is hoped that this study will make a significant contribution to knowledge because previous research in Greece has tended to focus on the state of special education in the country from the perspective of special education teachers (e.g. Avramidis and Kalyva, 2007; Kokkinos and Davazoglou, 2009; Athanasiadis and Syriopoulou-Delli, 2010; Miller et al. 2013). However, there is little evidence of research from the parents' perspectives regarding their views on the provision of disability services for their children. This is a key differentiating factor between this study and many previous research projects. The research aims to show that knowing more about the experience of parents is important for designing more specific interventions aiming to reduce parental stress. In this regard, empowering parents of children with ASD by helping them make use of the available sources of social support and providing assistance with coping strategies as well as enhancing their sense of control are particularly worthwhile endeavours (Dardas, 2014; Hope -West, 2011).

In the Greek context, there is limited research focusing on identifying how professionals deal with the practical problems that arise during the course of their interactions with the parents of children with ASD. That is, the literature fails to inform these professionals on the needs of parents raising a child with ASD in terms of their thoughts, feelings, and emotions about family life in these times of austerity (Gena 2006; Hitoglou et al., 2010; Syriopoulou - Delli et al., 2012). Most of the studies reviewed have employed qualitative methods, mainly using interviews with teachers (e.g. Hoogsteen and Woodgate, 2013; Ingersoll and Hambrick, 2011) and have not used quantitative or mixed methods approaches. This research addresses this gap by adopting a mixed method approach of questionnaires and interviews with different social agents namely, the parents and a range of professionals.

CHAPTER 3: Methodology

Giorgi and Giorgi (2003) argued that the goals of phenomenological research include: understanding and clarifying the situations and experiences that people live every day; offering detailed descriptions and accounts of the different phenomena and the contexts in which they occur; that the individuals that have the experience become themselves the focus of study. The aim is to examine the experience 'through the eyes of those who live it' (p. 248). Giorgi and Giorgi (2003) also argued that researchers need to realize how different levels of interaction can affect the meaning that individuals attribute to their experiences. From this view, phenomenology can be considered as a method of exploration and comprehension. At the same time Alexiou (2007) argued that for interpretive approaches, the unit of analysis is the individual and the actions of the individual, so the data gathered through the chosen methods of recording meaning and their processing will provide a ways to understand human actions. Consequently, their lived reality will be described through each individual's personal characteristics and interpersonal relationships, so that a better understanding and interpretation of social phenomena can be achieved.

With this in mind, the researcher used a mixed methods exploratory research design to get a better understanding of how parents and practitioners experience the world of children with ASD. The research questions required 'an exploratory interpretive approach in order to provide understanding with deep insights' (Newby, 2010, p.134). Interpretive approaches focus upon the way individuals interact, respond to and are affected by a situation. Human behaviours cannot be observed in the same way as natural phenomena but their behaviour can be interpreted in relations to their motives.

At the same time, Pourkos and Dafermos (2010) argued that methodology includes the theoretical assumptions and values that underlie a particular research approach. 'A methodology is always associated with specific epistemological and ontological schools of thought' (p.27). A phenomenological approach is qualitative, arguing that the social world is subjectively identified and constructed through the actions and interactions of its subjects. Tesch (1990) attempted to classify qualitative research on the basis of the main focus of interest. One of the four types that Tesch (1990) suggested is where the focus is the understanding of meaning or actions. This type of research includes interpretive research.

On the other hand, Kyriazis (1998, p.312) suggested that 'the complexity and the interaction of different levels of social reality bring to the foreground the need to combine different research methods in order to more effectively investigate the mechanisms through which they are interconnected'. Taking the same line of argument, Case and Light, (2011) suggested that 'there is no proper methodology or even the right set of methodologies. The choice of methodology (along with the underlying theoretical perspective and the associated research methods) is determined by the type of research questions that the researcher wishes to negotiate' (p.189).

This view supported a "third approach'' (Tashakkori and Teddli, 2010) a mixed approach, the combination of qualitative and quantitative approaches leading to research outcomes that with complementary benefits and no overlapping constraints. According to Greene et al. (1989), the goals behind mixed methodological approaches include: "development'' that refers to the sequential application of two methods in order for the results of the first to be used as a basis for the development of the second, for instance, a sample selection type of analysis and construction of research instruments. Development was a major consideration for this study. Questionnaires (quantitative) and interviews (qualitative) were used as research tools, giving numerical as well as qualitative results.

This approach involved the quantitative scrutiny of patterns which in turn formed the basis for qualitative exploration of the participants' views. In this regard, the purpose of this research was to explore the views held by parents of children with ASD and professionals who worked with children with ASD on different dimensions of the research issue. A combined approach made it possible to address and understand different aspects while at the same time the researcher was able to 'confirm the correctness of [her] insight and the legitimacy of [her] interpretation' (Newby, 2010, p.129).

Furthermore, Samaridis (2011) argued that the benefits of the mixed methods approach include revealing contradictions and unknown aspects of a reality as well as expanding the breadth of the research by increasing the information provided as data can be collected simultaneously or sequentially. This process has also to do with the integration of one or more stage of data. Based on the decisions about the data collection sequence, four mixed methods research designs have been identified:

- Triangulation Designs
- Embedded Designs

- Explanatory Designs
- Exploratory Designs (Borrego et al. 2009).

At the same time, Tashakkori and Teddli (2010) suggested that the choice of methods means selecting the best tools available to answer the research questions. A 'pragmatic approach of what works best' (Plano Clark and Badiee, 2010, p. 279) is what should help researchers make methodological decisions. With this in mind, the current research followed a mixed methods exploratory design to answer confirmatory and exploratory questions respectively. More specifically, the researcher wanted to examine the emotional challenges that parents' experience, the importance of the collaboration between parents and professionals as well as the difficulties encountered, the extent to which parents experience stigma as a result of having children with ASD and the context within which parents have to find answers to the difficulties they experience. The researcher formed more than one issue focused research questions. All five issues discussed referred to autism and considered as related but independent to each other. All the questions strengthened the researcher's understanding on how parents of children with ASD perceived the impact of autism on their everyday life.

The researcher gathered survey data from parents whose children attended special schools focusing on autism and professionals who worked at the same schools or the Centres for Differential Diagnosis and Support of Special Educational Needs (K.E.D.D.Y.). In the second strand of her study the researcher conducted interviews with parents and professionals and carried out a document analysis. The two phases of the research are 'highlighting the issues of need (quantitative data) as well as giving voice to these issues (qualitative data) (Plano Clark and Badiee, 2010, p. 284).

Since the researcher's area of work and studies is practice-oriented, her goal in this study was to explore the possibilities that can come from examining phenomena from every methodological approach that may help [her] to 'achieve the "fuller knowing" that advances knowledge and influences' (Sandelowski, 1993, p. 3). With this in mind the researcher took a pragmatic approach that 'focuses on real life research problems and prioritizes the purpose of the study rather than the use of particular research designs' (Klingner and Borgman, 2011, p.210). Having in mind "what fits best" for the research questions, the researcher decided upon a mixed methods sequential exploratory design. The quantitative and qualitative methods used in this mixed methods research complemented each other. The qualitative phase came after the quantitative findings in order to obtain more in-depth and specific individual

findings, echoing Hodgkin's (2008), view that 'quantitative data may assist in providing the big picture, but it is the personal story, accompanied by thoughts and feelings, that brings depth and texture to the research study' (p. 296). In this study the qualitative interview questions, developed from the quantitative findings, allowed a more in-depth investigation of the topic through the investigation of different aspects of the research questions than either a qualitative or quantitative approach alone. Using two research methods also triangulates the data from each source, hence reinforcing the overall results. The quantitative data has to do with "what" and the qualitative with "why and how", thus using both methods provide a more rounded picture of the questions under investigation. Fielding (2012) argued that mixed methods can offer depth of qualitative understanding with the reach of quantitative techniques. Moreover illustration convergent validation and analytic density are, according to Fielding, (2012) significant reasons for using mixed methods.

At the same time, Klingner and Borgman (2011) pointed out the difficulties of implementing mixed methods. For instance, it can be a time consuming process that requires the researcher to be familiar with analyzing both kinds of data. It also is a complex research design that can be difficult to plan and implement. However, when the design is exploratory and sequential, the steps fall into clear separate stages and the design and results are easier to report and describe.

Moreover, Jick (1979) offered Denzin's (1978) definition *triangulation* as the combination of methodologies in the study of the same phenomenon (in Jick, 1979, p. 603) and argued that the 'effectiveness of triangulation rests on the premise that the weaknesses of each single method will be compensated by the strengths of another' (p.604).

Cohen et al. (2007) defined triangulation as 'the use of two or more methods of data collection in the study of some aspect of human behaviour. The use of multiple methods or multi-method approach helps the researcher in explaining more fully the richness of human behaviour' (p.141). Denzin (1994) claimed that triangulation can be seen as the application and combination of different research methodologies in order to investigate the same phenomenon (p. 511).

In this study methodology and data triangulation was used. Two data collection methods (questionnaires and interviews) as well as several sources of evidence (questionnaires responses from parents and professionals; interviews with parents and professionals; document analysis**)**, triangulate and confirm the findings. Each data

source provided data in response to the same research question, offering more evidence. Using methodological and data triangulation enhanced the credibility of the findings by giving strength to the interpretations that emerged. Multiple methods were used to identify questions, or supplementary queries (Robson, 2007, p. 442) or the possibility of new aspects of a phenomenon since the multiplicity of data and analysis can reveal deviation from established approaches.

3.1 Research Design

The aims of the study were to examine parents' and professionals' perceptions about the nature of the difficulties faced by the parents of children with ASD and the factors that supported or hindered the effective collaboration between parents and professionals in Greece during austerity. In this chapter, an account of the methodology of the research is provided along with a discussion of the strengths and the weaknesses of the research design and methods. Simmons (2001) argued that at the beginning of the research project it is necessary to identify the most appropriate method for the study we intend to conduct. The decision about the method will be determent by the time and budget available as well as the subject of the research.

Gillbert (1993), cited in Silverman (1998) suggested that if the aim is to explore people's wider perceptions, then qualitative methods are more appropriate. However, King et al. (1994) argued that 'most research does not fit clearly into one category or the other. The best often combines features of each' (p.4). In the same way, Wisdom and Creswell (2013) also claimed that 'the term that "mixed methods" refers to an emergent methodology of research that advances the systematic integration, or that "mixing", of quantitative and qualitative data within a single investigation or sustained program of inquiry' (p.1)

Moreover, the definition offered by Creswell et al. (2003) suggests that 'a mixed methods study involves the collection or analysis of both quantitative and qualitative data in a single study in which the data are collected concurrently or sequentially, are given a priority, and involve the integration of the data at one or more stages in the process of research.' (p. 212,emphasis *in original*, cited in Lund, 2012, p.156). Driscoll et al. (2007) also argued that 'mixed methods designs can provide pragmatic advantages when exploring complex research questions. The qualitative data provide a deep

understanding of survey responses, and statistical analysis can provide detailed assessment of patterns of responses' (p.26). The rationale behind the choice of mixed methods for this study is that neither quantitative nor qualitative methods are sufficient by themselves to capture the trends and details of what it means to care for autistic children. When used in combination, quantitative and qualitative methods complement each other and provide a more complete picture of the research problem.

Searing et al. (2015) suggested that 'the examination of the support needs of caregivers and the supportiveness of existing resources is best informed by self-reported scales indicating perceived support than objective indices of support' (p.3694). With this in mind, this study used a sequential explanatory mixed methods design, consisting of two distinct phases. The quantitative, numeric, data were collected and analyzed first, before the qualitative data were collected and analyzed second in sequence, and so helped explain, or elaborate on the quantitative results obtained in the first phase. Thus, the quantitative data and results provided a general picture of the research problem, while the qualitative data and its analysis refined and explained the statistical results by exploring the participants' views regarding caring for children with ASD in more depth.

Kelle (2006) suggested that it can be useful when a mixed methods research design is used to start with a quantitative study, followed by a qualitative inquiry. But she also points out that the 'problem of quantitative research addressed by this design is the frequent incomprehensibility of statistical findings, which are often difficult to understand without additional sociocultural knowledge' (p.308). This is why priority was given in this study to the qualitative approach through interviews, which helped a better understanding of the results obtained in the first phase. The quantitative and qualitative phases were connected by selecting twenty parents and forty professionals to respond to an interview protocol that was based upon the results provided in the first, quantitative, phase of the research.

According to Pole and Lampard (2002) the question 'what counts as data?' serves a number of purposes in the context of this research design. It made the researcher sensitive in terms of the available data and forces her to think beyond the usual sources giving emphasis in the relationship between method and substance. The researcher has to think about how she would collect the data as well as about the contribution that her research will make to knowledge. Because this research aims to capture rich data from the participants concerning parental and professionals' attitudes towards children with ASD's educational and social needs, a mixed method design was

adopted. The mixed methods approach was deemed appropriate as each research question needs to be explored thoroughly using a range of techniques. Semi-structured interviews with selected participants, a questionnaire and documentary analysis were thus selected to triangulate and strengthen the robustness of the study.The objective of using the above-mentioned methods was to ensure that: a) the imperfections of any one method are offset by the other and b) validity through triangulation is achieved (Bryman, 2012).

3.1.1 Sample/Participants

"A purposive sampling strategy", (Patton, 2002), was adopted, comprising one hundred parents of children with ASD and one hundred professionals working with ASD children. The professionals included twenty special teachers, twenty psychologists, twenty social workers, twenty special educators, ten occupational therapists, twenty speech therapists and ten children's psychiatrists. Such a sample was intended to cover the variety of interests in relation to the practical considerations faced by professionals dealing with children with ASD on a daily basis as well as the challenges for parents and the experiences of sufferers themselves. The research was conducted in three schools specializing in children with ASD: one urban school and two suburban mixed Special Education Schools (SES), and three K.E.D.D.Y. (Centres for Differential Diagnosis and Support of Special Educational Needs) located in different areas of Athens in the Attica region of Greece.

These settings were selected because they had multidisciplinary teams to conduct assessments and support children with ASD. The parents deemed eligible to participate in the study were the biological parents of children diagnosed with ASD, aged 7 to 17 years attending state schools (primary or secondary). The paper work related to the enrolment of a child in an SEN school was made available to the researcher, which told her about the child's diagnosis, and on this basis she approached the child's parents. She explained the purpose of the research and guaranteed the confidentiality of the research and their anonymity to the parents. It was made clear to the parents that any other conditions that their child might experience were not relevant to this study and would not be part of the interview questions. Mothers and fathers who participated in this study were not married to each other except where clearly stated by the researcher. Such an occurrence was down to chance and then the participants were interviewed together. The vast majority of interviews had in a very open and emotional atmosphere

whereas being part of the same household might have made it more difficult for participants to express themselves openly and honestly on a sensitive issue out of respect to the feelings of their significant other.

The criteria for selecting the professionals were: working in special schools for children with ASD and/or K.E.D.D.Y. centres within the suburbs of Athens and with professional experience of at least ten years. As a professional (special teacher), the researcher was in a position to liaise with the aforementioned people hence gain access to those most significant in children with ASD's lives.

Punch (2009) argued that in quantitative sampling, representativeness is a key concept. 'Sampling to achieve representativeness is usually called probability sampling and while different strategies have been designed to achieve it, the main one is some form of random selection which is done to ensure representativeness. Stratifying population along different dimensions before random selection produces stratified random samples' (p.251). The nature of this research allowed the use of a stratified random sample. The fact that the parents who participated in this study have children who attend the three special schools for autism that can be found in Athens divided the sample into three manageable groups, and then random sampling from each group was used to select 100 parents. Patton (1990) argued that sample size depends on usefulness and credibility within the available time and resources, and that purposive sampling depends upon the purpose and rationale of the study and the strategy used to achieve it. The sampling strategy was heterogeneous (Robson, 2002), whereby different kinds of professional were chosen to represent types of provision, and parents with children with ASD. The aim was to achieve the maximum variation of data sources and provide a comprehensive picture of perceptions and practices from diverse sources. Choosing and having access to a broad range of participants early in the study helped the researcher to plan sampling for later stages of the research.

Guba and Lincoln (1985) also suggested that the size of the sample depends on the information provided. The sampling is terminated when no new information is on offer. Thus redundancy was the primary criterion. The researcher stopped including new units in the sample when repetitive patterns of information appeared.

Forty (40) professionals who agreed to be interviewed worked in three special schools for children with ASD in different areas of Athens. All forty professionals had also completed the questionnaire. Twenty (20) parents of children with ASD agreed to be interviewed for the purposes of this study. All twenty (20) parents had also completed the questionnaire.

Regarding the sampling of professionals, Cohen et al. (2013) also suggest that 'organizing a stratified sample was a simple two stage process. Firstly the characteristics that had to appear in the sample should be identified. Secondly random sampling took place within those groups, the size of which being determined by the judgment of the researcher' (p.101). At the same time, Hartas (2010) suggested that 'when selecting participants we need to strike a balance between affordability and meeting the statistical objectives set by data analysis procedures. This means selecting a sample that is large enough but not too large so as to waste resources and time. Most crucially we should be realistic about the number of participants we can access and the nature of information we can obtain from them' (p.71).

The fact that the professionals were either SEN teachers or worked at a K.E.D.D.Y. in Attica facilitated the stratification in selecting 200 professionals. These professionals were operating under difficult circumstances in special schools or K.E.D.D.Y. centres. They therefore had to tread a thin line between following the special schools or K.E.D.D.Y. centres collaboration protocol (the formal rules/certain tasks of the partnership stated by the government FEK 449/2007 N. 27922/Γ6/ SEN Ministry of Education) and the needs of each child with ASD. Thus, special schools with children with ASD and K.E.D.D.Y. centres provide a suitable context to explore the dynamic nature of the collaborative process, where boundaries and identities are key features.

3.2 Methods of data collection

3.2.1 Questionnaires

The questionnaires were administered at the 1st Special ASD School, the 2nd Special ASD School and the 3rd Special ASD School, and A΄ K.E.D.D.Y., B΄ K.E.D.D.Y., and C΄ K.E.D.D.Y. At the start of the investigation, all targeted participants were asked to complete a questionnaire to acquire general background information about their experiences regarding ASD, to probe parents and professionals' perceptions of an ASD diagnosis and support, family-professional collaboration challenges, family needs, parental involvement, professional development and inter-professional collaboration. The questionnaires were adapted, for the parents, from the: Impact on Family Scale (Stein and Jessop, 2003) and Family Needs Questionnaire (Siklos and Kerns, 2006) and for the professionals, the Professional Autism Needs

Questionnaire (PAN-Q) (see Keenan et al., 2007). Although they were not standardized in the Greek context, they were important research tools within the context of research in England. However, the researcher tried to adjust them to the Greek reality by paying attention to the translation into Greek to achieve semantic equivalence. Semantic equivalence refers to retaining a similar meaning for each item in the cultures of interest after translating the instrument into the language of each culture (House, 2014). In this case, this meant ensuring the translation reflected the meaning/message of words as used within the Greek context. All the questionnaires were translated and then back translated.The participants were asked to read the information in the questionnaire and to answer all the questions. The analysis from both questionnaires, one targeting parents (see Appendix 5) and the other professionals (see Appendix 6), generated a general understanding of the above defined are of analysis as well as providing demographic information about the participants (Denscombe, 2003; Gray, 2004). In order to motivate the respondents, the researcher sent an introductory letter, along with the questionnaire, in which she described the purpose and nature of the research, ensured the anonymity of the respondents and that the data would be used only for the purposes of the research. Given that the sample of the study consisted of three special schools for children with ASD and three K.E.D.D.Y. centres and because the response rate was relatively low the researcher decided not to send a follow up questionnaire. In addition to the battery of closed questions, some open-ended ones were included to provide opportunities for the participants to introduce relevant issues for inclusion in the schedule for the semi-structured interviews (Creswell et al., 2003; Kumar, 2011). On their own, questionnaires as self-reported data, may be untruthful or biased (Munn and Drever, 2004) and hence it was deemed necessary to carry out semi-structured interviews not only to gain a deeper understanding of the focal phenomenon, but also to check the veracity of the responses. The parents were asked questions on personal characteristics, such as their relationship to the child with autism, level of education, marital status, changes in employment to support children with autism, child's siblings, the age of diagnosis of autism, child's gender and date of birth and mental health problems associated autism disorder. Furthermore, parents responded to the following scales: a) Family needs and emotional challenges, which assess family needs, parents' difficulties in dealing with the behaviour of their children, parents' reaction to the diagnosis of their child's disorder and the impact of the child' disorder on family life, b) Services and resources and educational provision, which refers to the importance of an educational

programme for supporting children with ASD, their satisfaction with remedial services, (c) parent-relationship interaction scale which consists of items that measure the satisfaction and experience with their relationship with professionals.

Pilot study Parents' questionnaire: 10 parents whose children had ASD and attended a SEN school, filled in and discussed the questionnaire with the researcher in January 2015. This school was excluded from the sample used for the main study.

Main study Parents' questionnaire: 100 questionnaires were distributed to parents of autistic children who attended three (3) SEN schools for children with autism (ASD) in Athens. The data were collected between October and December 2016. In this particular case, the aim of the survey was to explore how parents of children with ASD dealt with a number of issues related to their child's condition as well as what parents thought of the cooperation of professionals. 74 questionnaires were completed and returned, pointing to a good response rate.

Pilot study Professionals' questionnaire: 10 Primary SEN teachers, who worked at a SEN school, filled in and discussed the questionnaire with the researcher in January 2015. This school was excluded from the sample used for the main study. Five (5) professionals who worked at C΄ KEDDY discussed and filled in the questionnaire in February 2015.

Main study Professionals' questionnaire: 200 questionnaires were distributed to teachers at SEN schools for children with ASD and at A΄ KEDDY and B΄ KEDDY in Athens, between October and December 2016. The aim was to explore professionals' views of the difficulties that parents experience in various aspects of their lives as a result of their children's condition, as well as their own level of satisfaction regarding their cooperation with parents. 140 questionnaires were completed and returned. As a result, the researcher decided to make changes in the questions in accordance with the comments received.

3.2.1.1 Questionnaires: a rationale

According to Kent (2001) questionnaires can provide 'an accurate picture of the attitudes and opinions people hold as a guide to likely behaviour' (p.7) which is one of the objectives of this study. In deciding to send questionnaires to the group of people chosen for the study, the researcher made, according to Marshall and Rossman (1995) the assumption that 'the characteristic could be described or measured accurately through self-report. In using questionnaires the researcher relies totally on the honesty

and the accuracy of participants responses' (p.96). In order to limit to this possibility the researcher considered 'the specification of the exact nature of the enquiry the population on which it was to focus and the resources that were available' (Cohen and Manion, 1994, p.85).

Survey research involves 'bringing together three separate but interrelated roles. The client on behalf of which the research was undertaken, the researcher who undertook the research and the respondent to whom questions or information giving tasks were addressed' (Kent, 2001, p.6). Simmons (2001) also suggested that the researcher 'generally needs information about the research population in advance of the study in order to develop questions that are appropriate for the recipients'(p.87). In this case the researcher is a SEN teacher herself and a school principal, consequently had access to the information needed to develop a self-completing questionnaire. Her own background made her familiar with the reality of teaching children with SEN.

The aim of the study was to explore parents' and professionals' views of their experience of caring for children with ASD. Having decided upon the main objective of the study Cohen and Manion (1994) argued that the second phase of planning is related to the 'identification and itemizing of subsidiary topics that relate to its central purpose' (p.85).

Two questionnaires were topics selected in this study. The subsidiary topics selected in the questionnaire given to parents included family needs and emotional challenges, recourse to services and educational provision, and parent-professional interactions. These topics were addressed through 24 questions divided into five sections. The questionnaire given to the professionals focused on their professional development and training, in two sections. The questions were in sections with topic headings to increase the clarity of the aims and help respondents understand and respond quickly and easily.

The first section of the questionnaire addressed to parents (Questions 1-9) referred to closed factual questions aimed at gaining an understanding of the characteristics of the population. Filias (1996) argued that 'closed questions are the perfect choice when simple answers are needed as responses to questions aimed at grouping the respondents on the basis of a specific criterion' (p.154).

The second section of the questionnaire focused on the family needs of parents of children with ASD. The content of the questions was based on the literature. The second section question had a ranking scale. Simmons (2001) argued that 'a ranking

scale can be valuable when trying to ascertain the level of importance of a number of items' (p.93).

The next six questions formed the third section of the questionnaire and concerned the emotional challenges that a family with an ASD child experiences. All the questions were closed and regarded by the researcher as quick to fill in, categorize and analyze since the 'usefulness of a questionnaire depends on the quality of the questions' Altrichteret al. (2008, p.139). To this end, most of the questions in this section were scale variants using a 5 point likert - type scale in order to facilitate the analysis. Were this was not the case, a single or listed response (rather than a descriptive response) was required. Newman (1994) suggested that 'a complete reliance on closed questions could distort the results' (p.234).

The next four questions formed the fourth section of the questionnaire and referred to parents' views on educational provision and resources. Tuckman (1994) suggested that scales are devices constructed by researchers to 'quantify the responses of a subject on a particular variable' (p.196). The aim behind this section was to assess the level of parents' satisfaction and the level of importance for parents of a series of educational provisions and remedial services. The question referring to the benefits that the child has acquired as a result of the educational provision has the agree/disagree form. Floyd and Flower (1995) argued that the 'agree/disagree question form and its variants is one of the most used measurement strategies in survey research' (p.67). The same authors claimed such questions 'should be as well defined as possible in order to increase consistency of respondent understanding of the ideas' (Floyd and Flower, 1995, p.65/ibid).

The final section of the questionnaire refers to parent/professional interactions. Oppenheim (1992) suggested that 'the chief function of attitude scaling is to divide people into a number of broad groups with respect to a particular attitude and to allow the researcher to study the ways in which such an attitude relates to other variables in the survey' (p.187). A criticism leveled against scale responses is that they offer no metric or interval measures, so it is not possible to know how far the scores in the middle range of mildly positive to mildly negative are perceived by individuals. A possible response is to regard the scale as 'an interval variable in which the interval between each point on the scale was assumed to be equal'. It is actually called an *equal appearing interval scale* Tuckman (1994, p.197). All the questions in this section involved likert type scales. Kent (2001) suggested that 'researchers administer

questionnaires to the same sample of a population to learn about the distribution of characteristics attitudes or beliefs. These surveys are called attitudes surveys and their main aim is accurate description' (p.7). In this case the researcher wanted to gather information about parents' beliefs regarding what facilitated or were barriers to parents and professionals interactions, the characteristics that parents attributed to their working relationship with professionals, the level of parental satisfaction with their relationship with professionals and the quality of their relationship during the diagnosis of their child. These questions gathered information directly related to the research topic, which Sarantakos (1993) referred to as primary questions.

Finally, the questionnaire distributed to parents had two open ended questions. The researcher wanted to find out how parents describe their experience of raising a child with ASD, as well as what parents coping strategies were in the case of a difficult situation that might arise at home. The intention of the researcher was to take advantage of the benefits that open ended questions have to offer. Open ended questions are used, according to Stacey, (1982, p.80, cited in Simmons, 2001) when 'the issue is complex where relevant dimensions are not known' (p.94). In this case, the issues were sensitive and complex and the researcher wanted to use open ended questions as a step to access qualitative data before the interviews. Becker (1989) as stated in Sarantakos (1993) argued that open ended questions produce 'a large amount of information, which requires time and effort to evaluate, they are time consuming and the responses are difficult to justify' (p.165)

The questionnaire distributed to the professionals was much smaller and divided in two sections. The first section referred to the professional background of the participants and consisted of five closed questions. The questions were quick to fill in and easy to answer. However, the researcher had to keep in mind that 'respondents might give false information in order to display increased ability' Fillias (1996, p.152). The final section of the questionnaire consisted of three questions about the professionals' views on the difficulties they thought parents experienced and the level of satisfaction they felt from their working relationship with the parents. Two of the four questions can be regarded as fixed alternatives. Sarantakos (1993) argued that although these questions are easy regarding to administer and code, their limitations need to be considered, more specifically, 'difficulty in covering all possible answers, restriction of the freedom, creativity and expressiveness of the respondents, and high chance of guessing the answers' (p.165). The last two questions where scale questions

referring to their level of satisfaction regarding the cooperation between parents and professionals and the impact of ASD on various aspects of their lives.

Cohen et al. (2013) argued that a questionnaire is a useful instrument for representing a wide target population. Collecting questionnaires provided descriptive and inferential information and gave the researcher the opportunity to manipulate key factors and variables. For this study questionnaires were given to a large sample of parents and professionals as a first step in discussing among other issues factors that hinder parent professional co-operation. Questionnaires offered structured numerical data and correlations can be ascertained. The distribution of a questionnaire does not need the presence of the researcher. It offers the opportunity 'to take a general purpose or set of purposes and turn this into concrete researchable fields about which actual data can be gathered' (p.318). The questionnaire can be regarded as a relatively accurate instrument due to piloting and revision. These strengths can be counter balanced by the time needed to plan and develop and refine the instrument the lack of flexibility in responses and the increased non response rate.

3.2.2 Interviews

Semi-structured interviews conducted with 20 parents and 40 professionals who completed the questionnaire and agreed to be interviewed. As explained above, the purpose was to discuss their experiences, feelings and the strategies they followed in order to cope with children with ASD in these straitened times. The interview schedules were drawn up from the literature and the questionnaire responses to generate rich data on the issues of interest, specifically: the diagnostic process, family social interactions/emotional challenges and coping mechanisms, parents' and professionals' perceptions regarding ASD support and provision, inter-professional and parent-professional collaboration, parental involvement, the impact of Greek special educational legislation and policies, and the challenges and development of professionals (see Appendix 6). The interviews were drafted based on the questionnaire responses before being modified. In addition, the researcher in order to familiarize herself with the salient issues and inform the final version of the interview guidelines, a brief pilot study was carried out, as explained below. By their nature, the questions in interviews are intended as a guide to develop dialogue and hence, unscheduled follow up questions can follow a new topic of interest or when the interviewer wants further

clarification regarding a particular matter. Exploring the perspectives of participants from different backgrounds elicited rich, in-depth data for analysis and interpretation on specific issues including ASD support and provision, family/professional challenges, parent-professional interactions and coping mechanisms for children with ASD.

Pilot study Parents' interviews: Four (4) parents whose children had ASD and attended a SEN school were chosen at random in January 2015. This school was excluded from the sample used for the main study. The interviews took the form of a conversation. The interviewees were informed about the nature and the purpose of the study. They were given the opportunity to make any points they wanted to and then the researcher tried to formulate the questions for the main study interviews based on their points.

Main study Parent interviews: Twenty (20) parents who had completed the questionnaires and whose children attended a special state school for children with ASD agreed to be interviewed between November and December 2015. The interviews were semi-structured and the duration of each interview was 50 minutes.

Pilot study Professional interviews: Three (3) SEN teachers and two (2) health professionals who all worked at the same school filled in and discussed the questionnaire with the researcher twice within the space of two days during the second week of February 2015. The interview took the form of a discussion between colleagues and the questions were formulated on those grounds.

Main Study Professional interviews: Forty (40) special education teachers who worked at the three special schools for children with ASD and professionals who worked at KEDDY centres in A΄ KEDDY, B΄ KEDDY and Piraeus KEDDY were interviewed in January-February 2016. An interview protocol was followed and the duration of the interview was 45 minutes.

3.2.2.1 Interviews: a rationale

The interview, according to Robson (2002), 'is a conversation with a purpose' (p.228). Cannell and Khan (1968) defined interview as 'a two-person conversation initiated by the interviewer for the specific purpose of obtaining research-relevant information, and focused by him/her on content specified by research objectives of systematic description, prediction, or explanation' as stated in Akbayrak (2000, p.1). Parents and professionals were interviewed in this study in to get an understanding of the needs and difficulties parents of ASD children experience. Robson (2002) also suggested that face to face interviews 'offer the possibility of modifying one's line of

enquiry following up interesting responses and investigating underlying motives in a way that postal questionnaires cannot' (p.229). In this study, interviews were used in conjunction with questionnaires 'to get a deeper and better understanding of the reasons respondents offered the answers they did' (Kerlinger, 1969 cited in Cohen and Manion, 1994, p.273). Patton (2015) also argued that interviews offer flexibility and spontaneity. 'Questions can be personalized to deepen communication with the person being interviewed and to increase the concreteness and immediacy of the interview questions' (p.437).

Further, Braun and Clark (2013) claimed that 'the goal of an interview is to capture the range and diversity of participants' responses in their own words' (p.79). But Miles and Huberman (1994) raised caution when claimed that 'if you are new to qualitative studies and are looking to a better understood a phenomenon within a familiar culture, a loose inductive design is a waste of time' (p.17). This was the reason why semi-structured interviews were chosen for this study, conducted with different stakeholders in order to examine effectively people's beliefs, values and practices. Through these interviews, the parents and the professionals had the opportunity to express those experiences, their feelings about these experiences and the strategies and actions that they took in order to cope with children with ASD. The interview is regarded as the most valid method of data collection because the responses help shape a more complete picture of the issue investigated (Cook and Campbell, 1989). At the same time, the process can be time - consuming in collection and analysis, and gaining access can become a challenge (Powney and Watts, 1990). Interviews provided the opportunity to cover a broader range of issues and discover things that we could not find out through observational methods (Hartas, 2010). In this study, interviews helped support the questionnaire data (triangulation) while allowing more detailed and specific probing into the topics that emerged from the questions.

Braun and Clark (2013) argued that the semi structured interview is the dominant form for qualitative interviews (p.78). Robson (2002) also claimed that a semi structured interview gives the interviewer the opportunity to prepare a set of questions before the actual interview 'but s/he is free to modify their order based upon his/her perception of what seems most appropriate in the context of the "conversation", make changes in the wording, leave out particular questions which seem inappropriate for particular interviewees or include additional ones' (p.231).

Mason (2002), as stated in Edwards and Holland (2013, p.3), suggested that despite the variations in style and tradition, all qualitative and semi-structured interviewing has certain core features, including: a thematic, topic centered approach

where the researcher has topics, themes or issues s/he wish to cover, but with a fluid and flexible structure. In this study, the topic of discussion was autism and the thematic units were needs and the problems parents of ASD children experience with regard to diagnosis, family, educational support and provision. Braun and Clark (2013, p.80) argued that the interview is ideal for sensitive issues and a skilled interviewer can get people to talk about them. An additional reason behind the choice of the interview as a method of data collection is an attempt to answer the question *how*, *in what way, which,* according to Iosifidis (2003) is one of the purposes of qualitative research. Kyriazis (1999) also argued that the interview gives the opportunity to gather detailed data on aspects of the subject under investigation. The semi-structured approach gave the researcher the opportunity to be flexible and allowed the participants to express themselves and how they felt about the circumstances they had to deal with. The researcher was able to gather through probes and further illuminating questions, the necessary information about the difficulties faced by parents and professionals as well as about what they thought was necessary for the situation to improve in future.

Questionnaires and interviews were considered to be appropriate for this study on the basis that questionnaires attempted to identify broad trends, while interviews tried to focus on these trends and gain an understanding of the processes underlying them. The methods selected provided the necessary flexibility to allow the findings to emerge from the data so they could be followed up to gain a deeper insight. Researchers doing qualitative research aim to achieve an understanding of how people make sense of their lives, delineating the process (rather than the outcome or product) and how they interpret what they experience (Merriam, 2009).

Interviews were a good tool for this research, because they helped the researcher to explore the key issues such as the needs of parents of children with ASD and their collaborative workings with professionals and the quality of services and provision for children with ASD in a time of austerity, systematically. Semi-structured interviews with Greek parents and professionals dealing with children with ASD were conducted on the basis of their experience of education policy decision-making and their availability to be interviewed and their links to three specials schools and three public K.E.D.D.Y. (Centres for Differential Diagnosis and Support of Special Educational Needs), drawn from urban and suburban areas of Athens. The focus on three state schools and three centres, purposely selected, was because it is believed that each single case is so complex that it can be understood only by investigating it in depth and by taking into consideration the important circumstances of the context (Stake, 1995). The reliability of the interviews was enhanced by carefully piloting them (Cohen et al., 2013) to enhance the reliability of the study. This enabled the researcher to revise the

interview questions where necessary, so that the questions could be understood in the same way by each participant. One threat to validity is the so-called *Hawthorne effect,* which refers to changes in the participants' attitudes and behaviour, i.e., becoming more cautious or socially aware, by taking part in the study.

Given the needs for substantial depth, using both questionnaires and interviews was deemed most appropriate for this study, because the combination of quantitative and qualitative approaches provides a better understanding of the research problems than either approach alone. Mixed methods encourage the investigation of multiple worldviews and are a practical and natural research approach. Mixed methods research is important because of the complexity of problems that need to be addressed, the rise in the interest in qualitative research and the practical need to gather multiple forms of data for diverse audiences. In this research, the researcher did not intend to solve a particular problem but to aid understanding by exploring a particular issue in detail (Cohen et al., 2013), in this case, a specific educational phenomenon as part of the social world. It was necessary to create opportunities to explore the relevant opinions, feelings, ideas and experiences of those involved, and consequently, to construct meanings from different, subjective views.

3.2.3 Document analysis

Key public policy documents regarding services and provisions for children with disabilities including autism, were analysed to assess the current provision for children with ASD. Moreover, recent government policy documents were analysed to examine any changes that had happened during the austerity period with regard to disability provision and support. In addition, individual education plans (I.E.P.s) written by teachers, official school plans and government policy documents were scrutinized. Such school documents offer information on the ways in which professionals deal with the challenges presented by children with ASD. In general, the policy documents revealed:

- The changes in the resources allocated for disability services and provision.
- The nature of policies that support parental participation or children with ASD's inclusion in state schools.
- The training opportunities for professionals that were offered to assist them in acquiring the professional competence necessary in the area of autism.

The researcher was aware of the possibility of having only limited access to some documents, as well as the bias that may be contained within them, both of which

could impact upon the study in terms of the analysis (Creswell, 2009). Further, some documentary evidence for this research is in the public domain (for example, governmental policy regarding SEN support), whilst some may be subject to restricted access (such as children's statements of special educational needs) which could further hinder access to data. The documentary data was compared with the interview findings from parents and professionals who were dealing with children with ASD to identify consistencies and anomalies between the two sources of data.

Lambert (2012) argued that 'analyzing documents involves what other people have written or created and using the results of your analysis as data. Educational documents that can be used in this way include among others lesson plans government documentation and policy documents' (p.107). The researcher needs the capacity to identify pertinent information and to separate it from that which is not relevant (Corbin and Strauss, 2008). The current 3699 (FEK A΄ 199/2-10-2008) special education Law and the previous one 2817 (FEK A΄ 78/14-3-2000) were used as sources of information. The school policies of the three special schools for children with autism coupled with the IEPs of the children who attended the schools were also available to the researcher. The researcher decided to focus on the legislation regarding special education as it works as it represented a framework of practice for those in the field of SEN education. The school policy represents the school's commitment toward their students and the nature of services that the school has to offer to them. The use of IEPs was considered important because they revealed how the needs of individual children were actioned.

The researcher considers IEPs to be an example of effective cooperation between parents and professionals. Robinson and McKartan (2011) suggested that due problems related to the researcher such 'as bias, partiality, reliability and interpretation, documentary research has been marginalized in educational research' (p.197). In the same line of argument, Bowen (2009) highlighted the difficulties the researcher faces when 'is expected to demonstrate objectivity (seeking to represent the research material fairly) and sensitivity (responding to even subtle cues to meaning) in the selection and analysis of data from documents' (p.32).

Document analysis is often used in combination with other qualitative methods as a means of triangulation. Triangulation helped the researcher corroborate findings across data and thus reduce the impact of potential bias. According to Patton (1990) triangulation helps the researcher guard against the accusation that the findings of a study are simply an artifact of a single method. In this mixed methods exploratory

study, document analysis was used in conjunction with questionnaires and interviews. Document analysis in the current study helped the researcher gain a better understanding of policy issues context factors and practices. Given that the data was collected from three special schools for autistic children in different areas of Athens, the documents included in the study were the schools' mission statements and policies as well as the current legislation for autistic children regarding parallel support. Finally some of the children's IEPs were also read by the researcher.

Bowen (2009) suggested that 'documents provide background and context, additional questions to be asked, supplementary data, a means of tracking change and development and verification of data from other sources' (pp.30-31). In this study, looking through the related legislation worked as a valuable addition to the researcher's knowledge base. It also helped her get an idea of the extent to which there was development and change in the way the state viewed the concept of autism. At the same time, the researcher used the documents collected to contextualize the information gathered through interviews. The related legislation helped the researcher decide on the questions put to the professionals during the interviews and worked as a framework for the researcher when discussing the difficulties they face in everyday practice.

Bowen (2009) regarded document analysis as an efficient method characterized by availability and cost effectiveness, as in this particular study. The school policies were readily available to the researcher since she was regarded as a colleague by the interviewees. At the same time, the related legislation of 2000 and 2008 respectively along with the circulars related to parallel support were available to the researcher through the related web page of the Ministry of Education as well as the Government Gazette. Finally, after a meeting with the headmasters of the three schools, the IEPs of the children were made available to the researcher. This occurred after confidentiality and anonymity were guaranteed and the way that the IEPs would be used was clarified. The researcher offered finally the option to present the findings of the research to the three special schools when the research was completed.

Bowen (2009) also discussed insufficient detail, law retrievability and bias selectivity as the disadvantages of document analysis as a research method. In this particular study law retrievability was not something that the researcher did not have to deal with. Bias selectivity was expected insofar as the researcher wanted to study school policy which reflected the school's aims and goals. The only disadvantage was all three kinds of documents collected gave insufficient detail in response to the research

questions. Consequently, documentary analysis was used as a complementary/ additional method of data collection.

Bowen (2009) pointed out that 'document analysis involves skimming (superficial examination), reading (thorough examination), and interpretation. This iterative process involves elements of thematic analysis' (p.32). Thematic analysis was the approach used to analyse the interview data. Since document analysis was supplementary to the questionnaires and interviews in the study, the same codes and categories used in the interview data were also used in document analysis. Bowen (2009) argued that 'codes and themes they generate serve to integrate data gathered by different methods' (p.32).

3.3 Pilot Study

3.3.1 Questionnaires

Lambert (2012) argued that piloting means 'testing your methods and research instruments in advance and changing them as a result usually by giving them some kind of practice run' (p.138). Pole and Lampard (2002) also suggested that 'in the case of a set of items which are meant to form a scale, a systematic assessment of the scale's reliability and unidimentionality can be carried out' (p.111). Useful advice used in preparing the questionnaires was found in Robson (2002), and Hartas (2010), especially the advantages of simplicity. Simple, easy-to-read, unambiguous questions are important. Other precautions that can help a researcher create a strong and purposeful instrument were:

- a pilot study with the same type of subjects as the main study
- asking the pilot subjects for feedback to identify ambiguities and difficult questions
- recording the time taken to complete the questionnaire and to see whether it is acceptable
- discarding all unnecessary, difficult or ambiguous questions
- assessing whether each question gives an adequate range of responses
- checking responses can be interpreted in terms of the information required
- checking that all questions have been answered

- the re-wording or re-scaling of any questions that are not answered as expected, shortening, revising and, if possible, piloting the questionnaire again (Table 3.23 in Peat et al. 2002, p.123)

A pilot study was conducted with the aim of gaining early insights into the themes that would be most prevalent as the research progressed as well as checking whether the questions were clearly understood by the respondents. Drawing on the professional experience of the researcher and a review of the literature, a set of questions was dawn up structured around the topics of: the diagnostic process, family social interactions/emotional challenges and coping mechanisms, parent perceptions of ASD support and provision, parent perceptions of ASD treatment and its effectiveness, parent-professional interactions and parental involvement. The aim of the pilot study was to check whether the participants interpreted the questions as intended, and to analyse the issues that emerged from the data of the pilot in terms of the support provision and treatment of children with ASD. As a result of the responses, the working question schedule was amended to include fewer sections and other questions were added regarding parents' perceptions of ASD provision and support and parent-professional interactions. These areas were modified further, once the questionnaires had been returned and analysed.

Regarding the parent questionnaires the pilot study was conducted when they brought their child to school or before they collected her/him. The nature and purpose of the study was made clear to them and their anonymity and confidentiality were guaranteed. It was also made clear that in the current stage of the research, feedback about the questionnaire was more important than completing it. All the parents completed the questionnaire while discussing it with the researcher.

The professionals and SEN teachers were equally accommodating to the researcher's request to provide the information needed. The researcher conducted the schools by phone, visited the school and explained to the principal and the rest of the staff members the purpose and the nature of the study. The questionnaire was completed either during a free period or at the end of a working day. The researcher explained that comments regarding clarity of wording and structure of the questionnaire were welcomed at this stage of the research. The process in both cases lasted twenty minutes.

During the pilot study process, the open ended questions 'to what extent you find dealing with the following behaviours difficult?' and 'how did you react to the diagnosis of ASD?' were included in the questionnaire distributed to parents.

None of the participants gave any response to the question 'to what extent you find dealing with the following behaviours difficult?' Due to the poor result the researcher decided to change the form of the question to a closed one based on the literature review.

As for the second question, the participants were very descriptive and used metaphors in their answers. They expressed their emotions but almost all said that what they felt was very difficult to put in words. The way participants responded made it very difficult for the researcher to categorise their responses although the meaning of what parents said was very clear. In an attempt to increase the quality of the responses, the researcher decided to form another closed question using a range of emotions based on the responses given in the pilot study.

3.3.2 Interviews

Four (4) pilot study parents whose children attended a SEN school were chosen at random and agreed to be interviewed in January 2015. The data produced was not part of the main study. The interviews took place at the school at a time of their convenience. The pilot study participants were chosen on the basis of convenience and access. The aim was to refine the interview questions in order to get deeper insights into the issues being studied. The pilot study took place in parallel to the literature review. The researcher hoped that the final questions in the interview schedule would be informed by both prevailing theories and the issues raised by the views and opinions of the participants in the pilot study process.

As explained earlier, the interviews took the form of a conversation. Before the start, the researcher informed the parents about the nature and the purpose of the study. Their confidentiality and anonymity were guaranteed as well as the option to stop the process at any time they wished. The questions included:

- Have you experienced stigma and prejudice from other people?
- How has your child affected you and your family's lives in this period of austerity?
- What do you think is the most important obstacle to dealing with the challenges involved in raising a child with ASD?
- Does the existing educational legislation for Special Educational Needs (SEN) help your ASD child to receive appropriate educational support and provision?

- How do you see your relationship with ASD professionals?
- Are you actively involved in discussions about your child's treatment and educational interventions?
- What factors affect your parental involvement in the diagnosis of ASD and ASD educational support and provision?
- What kind of informal support do you need in order to be more effective in your role as your child's main care taker?
- What type of social network (extended family parent, organizations/groups, friends, church other social clubs) do you find to be supportive of your child's disability?
- What kind of support do you need to develop a social network for your child?
- What kind of training do you need in order to help your child improve his/her skills?
- What kind of help do you receive from the state in order to support your child with ASD?
- Could you please describe one experience in relation to accessing services?
- How do you think the support your child receives could be improved?
- Have you participated in a remedial programme with your child? How effective was the programme?
- How good do you think the services offered to your child with ASD were?

The conversations were taped and transcribed and the following patterns emerged: Parents felt that they did not need training but needed to understand better what autism is and what causes it. They also claimed they received very little help from the state regarding their children. All pointed out a lack of money, personnel and resources as reasons for the poor quality of services offered to their children. All three suggested that they had participated in remedial programmes with their children and clearly stated that it was a beneficial process for everyone. At the same time, they mentioned it was very expensive. Finally, although they admitted that it was difficult to access the services, none of them was willing to describe a particular experience.

Parents acknowledged that they were not aware of the legal framework and the rights granted them by law. They knew that that they had to turn to KEDDY for information and support, though they acknowledged it was rather limited.

- All acknowledged that they experienced prejudice and stigma from other people.
- All participants argued that they looked to the doctors and other specialists for

solutions to their problems due to the fact that they felt at a loss about what to do.

- Parents admitted that they did not know how to become effectively involved in their child's treatment and educational provision.
- Parents claimed that the question about what factors affected their parental involvement in the diagnosis of ASD and ASD educational support and provision covered too many issues to be discussed effectively.
- All participants were very clear about the kind of informal support they needed in order to be more effective in their role as their child's main carer.
- All participants were very clear about the significance of the social network and the type of social network needed in their attempts to be supportive of their child.
- The question: < Could you please describe one experience in relation to accessing services? > was not answered and as a result was omitted from the final interview guide.
- The question: < How do you think the support your child receives could have been improved? > was not answered and as a result was omitted from the final interview guide.
- All parents said that they had participated in a remedial programme with their child but they did not make any comment about its effectiveness.
- Parents claimed that there were too many questions and the interview process was time consuming.

These responses led the researcher to change the questions, either the wording or in some cases, the content of the questions included in the final version of the interview guide. The final version of the interview guide included fewer but more generic questions. The final version of the interview guide for parents was as follows:

INTERVIEW GUIDE FOR PARENTS

- Who do you think is the role of the state public services regarding the support of your child?
- What is the role of KEDDY in relation to the support of your child?
- What is the nature of the difficulties that you and your child face in your attempts to obtain support?
- Do you consider yourself to be the center of everything in terms of meeting his/her needs?

- Do you keep your pain and struggles private when dealing with everyday challenges?
- Do you experience bias and stigma from society at large?
- Are your relationships with others effective and supportive?
- Have you had emotional support from other parents of autistic children? What kind of external support do you need?
- What kind of expectations for the future do you have for your child?
- In your opinion, do the experts /professionals have the appropriate qualifications to deal with your child's challenges?
- Do you think that specialists and professionals can replace other informal support systems in our country as a result of the austerity measures?
- Do you feel the only support you get comes from the experts?
- What socio-economic factors affect your cooperation with professionals in these times of austerity?
- Have you noticed any changes in yourselves (e.g. attitude, behaviour) as a result of raising an ASD child?
- Please add any comments below.
- Thank you for your support.

As for the professionals, once again the criteria were convenience and access. Five (5) persons, three (3) special needs teachers and two (2) health professionals who worked at the same SEN school and had already completed the questionnaire agreed to be interviewed in February 2015. The professionals had been chosen at random and once again, the researcher used Patton's interview guide (1990) which was not shown to the participants. The fact that the researcher has been a special needs teacher herself for many years as well as principle of a special needs primary school made the professionals who participated at this stage of the study treat her as one of their own''. As a result, they were willing to participate and agreed for the conversation to be taped, transcribed and analysed by the researcher. The questions included in the pilot interview guide for professionals were as follows:

a) Are you satisfied with the in-service training you receive?

b) Do you feel confident enough to treat a child with autism appropriately?

c) What is your opinion about cooperation with parents?

d) Do you feel that there are any shortages in terms of resources in your school?

e) Do you have state support to help you do your work effectively?

f) Are you able to cooperate effectively with your colleagues inside as well as outside the school?

The following patterns emerged: All the professionals at this stage of the pilot study were aware of the school policy and the 3699/2008 law and used them as the framework for their answers. The professionals suggested that although they were satisfied by the training they had received, more substantial training in autism was necessary. Cooperation with parents could be difficult and the state does not help them enough, especially in austerity periods, to fulfill their roles and responsibilities. Finally, the lack of personnel and resources accounted for the difficulties in inter and intra collaboration between people and departments.

The responses the researcher received made her realise that her questions did not cover all the issues raised by professionals in their responses. As a result, in addition to the questions included in the pilot interview guide, more specific questions needed to be added to cover all the issues raised by the professionals. The final version of the interview guide given to professionals is below:

INTERVIEW GUIDE TO PROFESSIONALS

- How do you support children with autism in a time of austerity?
- Are you satisfied with the in-service training you receive?
- What are the biggest challenges you face as professionals, especially when working with children with autism?
- Do you believe that austerity policies affect your work in supporting disability?
- What are the factors that help your cooperation with other professionals?
- What are the factors that hinder your cooperation with other professionals?
- What are the factors that support your cooperation with parents?
- What are the factors that negatively affect your cooperation with parents?
- As professionals do you think that the parents of autistic children have difficulties in accessing the services provided?
- Have you experienced any changes in yourself as a result of your participation in the education and well-being of autistic children?

3.4 Ethical Considerations

3.4.1 Sensitive research

Cohen et al. (2013) argued that educational research can be sensitive as it can intrude into private spheres and deep personal experiences and that sensitivity exists 'not only in the educational topic under study. Conducting research is a matter of interpersonal relationships, continual negotiation, setbacks, modification and compromise' (p.121) and participants can be reluctant to participate because of the topic. The researcher did not face any difficulty speaking with the staff members or the principles of the three schools.

Despite the fact that this research focused on the sensitive issue of autism, the majority of parents were also willing to complete the questionnaire. An explanatory letter was included which guaranteed the confidentiality and anonymity of the responses and the purpose of research was clarified.

3.4.2 Doing the interview

Mishler (1996) referred to Cannell and Kahn's (1968) definition of an interview as an oral communication with a specific purpose focused on a particular subject. The researcher's knowledge and ease of communication had a significant impact on the success of the process. Mathers et al. (1998) pointed out that in a semi structured interview 'if the interviewee has difficulty answering a question or provides only a brief response, the interviewer can use cues or prompts to encourage the interviewee to consider the question further. In a semi-structured interview, the interviewer also has the freedom to probe the interviewee to elaborate on the original response or to follow a line of inquiry introduced by the interviewee' (p.2).

This research complies with the guidelines of the British Educational Research Association (BERA, 2011). To meet these standards, ethical considerations were taken into account as follows:

- participants informed that their involvement was optional, and that they could withdraw at any time;
- written consent was provided by the participants prior to the research;
- participants were made aware of the nature of the research and the approach taken, emphasizing that the study would respect their cultural values;
- participants were informed that the data collected would be kept anonymous and not disclosed outside the groups;

- Official approval was sought from the Special Education Department of Ministry of Education in Greece which provides research access to the special schools and K.E.D.D.Y. centres.

The researcher had no difficulty accessing the three special schools for children with ASD and conducting the interviews. The researcher was treated as a colleague and permission and time arrangements were made via telephone. The researcher had a brief meeting with the school principal prior to conducting the interviews where she explained the purpose of the research and the topics covered by the interview.

Although the researcher had decided upon the content of the interview guide, the reaction from the respondents indicated that the breath of the issues raised could not be sufficiently covered within the time allocated for the interview.

3.4.3 The researcher as an instrument of data collection

Patton (2015) referred to empathic neutrality which he defines as 'understanding a person's situation without judging the person and communicating that understanding with authenticity to build rapport trust and openness' (p.457). With this in mind, the researcher in this study had to fulfill two roles. She acted as an outsider, peering in from the outside, trying to find out what was taking place. This role demanded that she maintained objective and adopted an impersonal approach. At the same time, the researcher due to her experience in the field, was perceived as an insider. However, this could lead to bias in the interpretation of what the respondents said and how they behaved, which could influence the study outcomes. This dual engagement needs to be acknowledged, otherwise the researcher 'may remain innocently unaware of the deeper meaning and commitment of what they say or how they conduct their research' (Pring, 2003, p.90). Her position as a researcher/ professional within the field was carefully considered and she consulted knowledgeable colleagues to check and challenge where necessary, her thinking and practice.

Another issue that the researcher had to take into account was her role was to listen attentively to what the respondent had to say. 'By utilizing attending behaviour to enhance individuals' self - respect and to establish a secure atmosphere the interviewer facilitates free expression there by enhancing validity' (Anderson, 1998, p.195).

3.5 The reliability and validity of the study

3.5.1 Questionnaires

Hartas (2010) argued that an important consideration of a quantitative research design 'is to ensure that the methodological approaches taken to address the research questions are consistent trustworthy and meaningful. To this end, the reliability and validity of a study are important criteria to judge its quality' (p.71). In quantitative research, reliability means consistency (Punch, 2009, p.244). It refers to the extent to which the instrument will provide the same results every time it is administered. Validity, on the other hand, refers to the extent to which 'an instrument measures what it is claimed to measure' (Punch, 2009, p.246). Punch (2009) continued to argue 'the validity question only applies to the inference we make from what we observe' (p.246). The understanding of face validity was used for the introductory questions on both questionnaires used in this study. Face validity, according to Singleton and Straits (1999) refers to 'a personal judgment that an operational definition appears on the face of it to measure the concept it is intended to measure. Few would dispute the face validity of common indicators of variables such as age gender and education' (p.121).

In this mixed methods exploratory study, the questionnaire was used as a research instrument in order to explore parents' and professionals' opinions on the needs and the difficulties parents and professionals experienced in caring for an autistic child. If content validity concerns 'the extent to which a measure adequately represents all the facets of a concept' (ibid), each section of the questionnaire addressed a different aspect of the same issue. What the researcher wanted was 'to create valid and reliable operational definitions for variables for which the researcher wanted to investigate the interrelationship' (Black, 1999, p.216).

Furthermore Pole and Lampard (2002) discussed content validity, raised the issue of how many indicators cover the breath of a concept. They argued that any form of validity involves a degree of subjectivity (p.101) and that the decision made by the researcher reflects the degree of confidence s/he has in the indicators (p.102). In this case, the literature review as well as the interests of the researcher on the needs of parents and professionals who care for children with autism was used as a framework for the choice of indicators. Another way of enhancing validity was through standardization (Pole and Lampard, 2002). This has to do with the steps involved in designing, administering and analyzing a questionnaire. If a researcher is able to discuss all the above issues concerning the conditions under which a survey was conducted,

then s/he will be able to show 'the use to which the measure is put' (De Vaus, 1991, pp. 54-55).

Regarding reliability Hartas (2010) described test- retest reliability as the process of giving 'two very similar or equivalent tests to the same participants at two different points in time' (p.77). With this in mind, five (5) parents whose children attended the same SEN school, five (5) teachers and five (5) professionals who all worked at the school filled in and discussed the questionnaire with the researcher twice within the space of two days during the second week of February 2015. The school was excluded from the main sample of the study. Validity and reliability were also increased through the pilot study.

3.5.2 Interviews

The reliability of interview schedules can be achieved, according to Silverman, (2001) by pre-testing the interview schedules and inter-rater reliability checks on the coding of answers to open ended questions. Silverman (2001) also suggested that it is important that each respondent understands the questions the same way and that responses can be coded with certainty. The pilot study was used as a means to adjust and then test the interview guide. In addition, two (2) colleagues from the same SEN school read different parts of the interview transcripts. They were introduced to the coding system used by the researcher and then asked to allocate the responses to the codes, as they understood them.

Furthermore, interviews also have to satisfy the criterion of low inference description. This can be achieved through tape recording all face to face interviews and transcribing the tapes, to ensure a reliable analysis (Silverman, 2001). These techniques were used by the researcher in this study. Finally, another way to strengthen validity was respondent validation. One parent, one health professional and one SEN teacher agreed to read their interviews and comment upon them if they wished. The interview data was analysed through the use of thematic analysis which is discussed in the data analysis section of this chapter.

In an attempt to enhance validity, the researcher invited one of the four parents, one special needs teacher, and a health professional to a second meeting in a free period during the last week of September 2015. The researcher asked them to read parts of the transcribed data and had another brief conversation about their views.

In terms of validity, Guba and Lincoln (1985) and Marshal and Rossman (1995) presented four constructs that reflect the assumption of qualitative research. Creditability refers to the ability of the researcher to 'demonstrate that the enquiry was conducted in such a way as to ensure that the subject was accurately identified and described' (Marshal and Rossman, 1995, p.143). Every effort was made by the researcher to set clear parameters regarding the study sample.

Guba and Lincoln (1985) according to Marshal and Rossman (1995) referred to transferability as the 'demonstration of the applicability of one set of findings to different contexts' (p.144). Due to the nature of the research, generalization of the findings is problematic, but triangulation through multiple data methods, as described earlier, aids the validity of the research. Miles et al. (2013) pointed out that the aim is to pick triangulation sources that have different foci and different strengths, so that they can complement each other. Triangulation can help the researcher's findings from different sources enhance the trustworthiness of the analysis.

Moreover, through dependability 'the researcher attempts to give an account of the changes in the issue chosen for study. This is acceptable in qualitative research under the premise that the social world is under construction. On this basis, the concept of replication is problematic' (Guba and Lincoln, 1985, p.146). Finally, confirmability has to do with 'objectivity. It is about asking whether the data helped confirm the findings' (Marshal and Rossman, 1995, p.146). One way to deal with the problems discussed above could be the use of a checklist. Maxwell (1998) argued that the use of a checklist helps to deal with validity threats in the sense that it tests the conclusions. The idea is to test the conclusions by looking for evidence that challenges the conclusions and makes the threat implausible (pp. 92-93). Member check involves the systematic solicitation of the views of the participants in the study about the data, results and conclusions. Three parents and two professional interviewees in this research were willing to look at the transcripts and the researcher made notes in an extra meeting at the SEN school where either they worked or their children attended. Finally, the use of rich data in interviews implied the use of detailed transcripts instead of notes of what the researcher regarded as significant. The aim behind using long extracts is to provide a test of the developing argument rather than a series of supporting instances.

Table 3-1: Interview procedure

Interviews

Validity	Reliability
Constant comparative method	Pre-test of the interview schedules through pilot study
Respondents' validation	Check for coding of the open ended questions
	Low inference description
	Tape recording of the interview
	Transcribing the interview and presenting long extracts of the data in the research report.

3.6 Data analysis

This section discusses the way the data collected through interviews and questionnaires was analysed. The quantitative responses in the survey data were processed using SPSS software in order to establish their frequency of occurrence; there were then subjected to statistical analysis, where appropriate. The qualitative interview data aimed to investigate the common themes and issues emerging from the different stakeholders' perspectives. The semi-structured interviews were audio-recorded, transcribed and translated to English by the researcher in an attempt to familiarize herself with the data. By focusing on the meanings conveyed by the participants, the key themes were identified through a grounded analysis approach (Hartas, 2010; Bryman, 2012).

Patton (1990) claimed that 'there are no absolute rules except to do the very best with full intellect to fairly represent the data and communicate what the data reveals given the purpose of the study'(p.372). This does not mean that there are no guidelines to assist in analysing the data.

3.6.1 Analyzing Questionnaires

Cohen et al. (2013) suggested that editing questionnaires is necessary to identify errors made by the respondents. Moser and Kalton (1977, in Cohen et al., 2013, p. 348) referred to three different editing tasks: completeness, which means ensuring that every question has an answer; uniformity, which has to do with the way participants interpreted the question; finally, accuracy refers to checking whether or not all the questions have been answered accurately. Computer packages can help process survey

data. Cohen et al. (2013) claimed that a computer package offers the ability to create store and reformat files as they are created or change at ease.

Tolmie et al. (2011) suggested that statistics provide appropriate tools for planning the process of collecting, describing, analyzing and processing data, that is, a set of methods and rules to organize the data collection to make it concise and effective for both presentation and analysis, and to produce useful conclusions. The questionnaires were analysed using SPSS Statistics (22) as a first approach to discovering parents' and professionals' views of caring for children with autism.

Through the use of inferential statistics, the data were analysed in order to examine the relationships between variables. For the purpose of this study, independent T-tests and ANOVA analysis were conducted to examine statistically significant differences between the groups. Descriptive statistics were also employed to give an overview of what the data revealed. Punch (2009) argued that hypothesis testing is an important part of inferential statistics and a tool that allows the researcher to test the validity of his/her argument. With this in mind, a single sample t-test was used in this study in order to check the hypothesis related to the variance of a population. The estimate of the variance of a population is based upon the variance of a sample. The T-test could be used, according to Punch (2009) only when the sample is representative and the distribution is normal. Finally, ANOVA was used to compare the two groups of participants - parents and professionals - regarding dependent variables of interest. But Punch (2009) also pointed out that there are two sources of variance and 'the problem is to decide if the variance between the groups is larger than the variance within the groups. If it is, we can conclude that the groups differ; if not that the groups do not differ' (p.265). Independent T-tests and one-way ANOVA were used to determine whether there is a statistically significant difference between the means in two or more unrelated groups. When using the one-way ANOVA, it is important to consider similar parametric assumptions to the independent T-tests (Wilson and Maclean, p.390).

Finally, Punch (2009) argued that the method of data analysis is governed by the research questions. Rather than focusing on a single specific method, multiple methods were used in order to address complementary but different questions within the study.

3.6.1.1 Coding

The researcher used pre-coded questionnaires to allow the classification of the responses into meaningful categories. The coding process is, according to Ross and

Sullivan (1996) 'the first step in preparing data for computer analysis and in mapping out observation into data' (p.38). Kothari (2004) argued that 'nominal scales are simply a system of assigning number symbols to events in order to label them. They are widely used in surveys when data are being classified by major sub-groups of the population. Ordinal scales are frequently used in research relating to qualitative phenomena. Thus, the use of an ordinal scale implies a statement of 'greater than' or less than' (an equality statement is also acceptable) without our being able to state how much greater or less' (p.71). Furthermore, Robson (2002) argued that the categories included in the questions have to be mutually exclusive and exhaustive. For Singleton and Straits (1999) coding for computer analysis consisted of assigning numbers or symbols to variable categories. For closed questions, coding is 'straightforward' (p.457). In this study, a number was given to each questionnaire and each statement was considered as a variable that was coded separately.

As for the two open-ended questions, the development of a code involved linking theory to the data collected. All the responses were translated, transcribed, coded and subsequently categorized on the basis of the literature review.

3.6.2 Analyzing Interviews

Anderson (1998) suggested that 'the quality of responses, that is, their reliability and validity depends upon the interviewer. This is especially true if question or interview procedures are not standardized' (p.190). Reliability refers to the consistency exhibited by the researcher during the different stages of the research process. Reliability is difficult because no researcher conducts each interview in exactly the same way. Macmillan and Schumacher (1989) argued that making explicit aspects of the research design can be considered as a way to enhance the reliability of the data collected. These aspects include: 'researcher's role, informant selection, data collection and analysis strategies and analytical constructs and premises' (p.189). The reliability of interview schedules can be achieved, according to Silverman (2001), by pre-testing the interview schedules and inter-rater reliability checks on the coding of answers to open ended questions. Silverman (2001) also suggested it is important that each respondent understands the questions in the same way and responses can be coded without uncertainty. In this case, the pilot study was used as a means to adjust and then test the interview guide. In addition, two (2) colleagues from the same SEN school accepted to

read different parts of the interview transcripts. They were given to the code used by the researcher and then asked to apply the code to the responses. The school was excluded from the sample used in the main study.

Furthermore, interviews must also satisfy the criterion of using low inference description. This can be achieved through tape recording all face to face interviews and transcribing the tapes according to the needs of reliable analysis (Silverman, 2001). These techniques were used by the researcher in this study. Finally, validity was strengthened by respondent validation. One parent, one health professional and one SEN teacher read their interview tape scripts in Greek and commented upon them if they wished. The interview data was analysed through thematic analysis, which is discussed separately in the next section of this chapter.

3.7 Thematic analysis

Robson (1993) defined the *conceptual framework* as 'the main features of the research design that forces you to be explicit about what you think you are doing' (p.150).

Furthermore, Braun and Clark (2006) argued that that thematic analysis appears to be the most feasible way of analyzing interview transcripts; it is a method for identifying and interpreting patterns of meaning across qualitative data in detail (Clarke and Braun, 2014, p. 1202). Guest et al. (2012) suggested that thematic analysis moves beyond counting words and phrases to capturing something important about the data in relation to the research question. Furthermore, Braun and Clark (2013, p.202) argued that thematic analysis is flexible in the way it is carried out. The identification of themes can take place inductively (data driven) or deductively (theory driven). In this study, deductive coding was used based on the data collected through interviews and questionnaires. Braun and Clarke (2006) suggested a systematic way of doing thematic analysis that imposes high standards on the analyst. There are six steps in the process: a) familiarisation with the data; b) initial coding generation; c) searching for themes based on the initial coding; d) review of the themes; e) theme definition and labeling; and f) report writing.

This section describes the method of data analysis followed for the interviews. The six steps of thematic analysis were followed according to Braun and Clark's (2006) argument that 'clarity around the process and practice of the method is vital' (p.7). This

process is not linear but recursive, back and forth as needed throughout the phases (p.86).

Table 3-2 : Steps Taken in the Thematic Analysis process (Braun and Clark, 2006)

Steps Taken	Examples
Familiarisation with the data	Reading and translating data
Generating the initial codes	Grouping the responses of parents and professionals and identifying the initial themes within the content
Searching for themes in the initial coding	Organising the data into groups according to all the themes that appear in the data
Reviewing the themes	Deciding upon the strength of the data in relation to a theme
Defining and naming the themes	Deciding upon the main themes to be included in the research

3.7.1 Familiarisation with the data

This stage of the process involves *immersion*. This means repetitive reading of the data in an active way. In this study, the interviews were conducted in Greek, the mother tongue of the participants and the researcher. The interviews were tape recorded and the researcher listened to them again and again in order to translate them to English. The researcher did the transcription herself. Although Braun and Clark (2006) characterized the transcription process as 'time consuming, frustrating and sometimes boring' (p.17) it made the researcher familiar with the participants' way of thinking. All the recordings were of good sound quality which helped the transition from oral to written language, which had to be read analytically. Finally, Cope (2004) argued that transcribing the interviews would ensure that data analysis was carried out 'with an open mind instead of an existing structure'.

After producing the transcripts, the researcher checked the text against the audio tapes and made the necessary refinements, as suggested by Braun and Clark (2006) since 'what is important is that the transcript retains the information you need, from the verbal account and in a way that it is true to its original nature' (p.17). The transcripts were then translated in English and read many times analytically and critically to consider both the surface and the hidden meanings of the participants' words. At the same time, the researcher highlighted key phrases within the transcripts to facilitate the coding process. The researcher used the phases as memory aids as a starting point for coding and analysis and read and reread the raw data.

Table 3-3: Familiarization with the data: An example of the English translation of the original Greek

Austerity years	Χρόνια λιτότητας
Nowadays, services are sparing due to economic misery. We need to help parents accesses services and strongly assert their rights (Professional 39)	Σήμερα οι υπηρεσίες που παρέχονται είναι φειδωλές λόγω της οικονομικής δυστυχίας. Πρέπει να βοηθήσουμε τους γονείς να έχουν πρόσβαση στις υπηρεσίες και να ισχυροποιήσουν τα δικαιώματά τους. (Επαγγελματίας 39).

3.7.2 Generating initial codes

At this stage the analysis was based on the search for possible topic either latent or semantically linked. Here, the researcher combined different codes to look for possible themes or patterns that arise through the data. Some patterns could form major themes while others, sub-topics or sub-categories. Themes could arise as a result of the grouping of codes or categories and have a higher degree of interpretation than the more descriptive codes or categories.

The role of the researcher in seeking themes or patterns is significant; Ellis et al. (1997, in Braun and Clark, 2006) argued that themes do not exist in the data, but emerge from it. If themes and patterns exist somewhere, it is in the mind of the researcher, her thoughts about the data and the connections she makes to make sense of it. The researcher is invited to make connections, make meaning of the data and to comprehend it. The decisions the researcher makes are directly related to the choices, conclusions and interpretations s/he makes with regard to the data collected. These decisions, in turn, are based upon specific epistemological assumptions and the broader research planning - in this case, mixed methods exploratory research. Misher (1996) argued that whether the researcher decides to approach the data inductively or deductively is up to him/her. In this study, the interview schedule helped the formation of the categories initially and after the transcription, translation and labelling of the data, the initial categories were formed. An example from an interview with a parent shows is how the codes emerged (see Table 3-4). The extracts were translated from Greek.

Table 3-4: Generating initial codes: An example of an interview with a parent to show how the codes emerged.

Parent reaction to ASD diagnosis	Σκότωσαν μια εικόνα που είχα για το παιδί μου και έπρεπε να χτίσω μια άλλη, δεν ήξερα ακριβώς ποιο είναι το παιδί μου. Αισθάνθηκα ό,τι αυτό το παιδί που είχα, έχει πεθάνει και έχω ένα άλλο παιδί στα χέρια μου που έχει το ίδιο πρόσωπο, που δε ξέρει όμως την ψυχή του. (Γονέας Β)	My child, as I knew him, was not there anymore. I had to get to know a different child whom I did not recognize. It felt as if my child was dead and I was confronted with another child who looked like my own but had a different soul. (Parent B)
Future outlook for ASD	Έχω άγχος εάν η βελτίωση θα φτάσει σε τέτοιο σημείο, ώστε να μπορεί πλέον να ζήσει και μόνος του. Να είναι αυτόνομος. (Γονέας Ν)	I am anxious whether his improvement will reach a point that will make him capable of living on his own, be autonomous. (Parent N)
Parent needs	Να υπήρχε κάποιος φορέας να υποστήριζε το παιδί μου και εμένα. Στην εκπαίδευση του παιδιού μου, κανείς δε βοήθησε. Να υπήρχε η δυνατότητα για εξωτερικές κοινωνικές συναναστροφές, κάτι που δεν έχει υλοποιηθεί, να πάνε μαζί τα παιδιά να ψωνίσουν μόνα τους, να πάνε στα Goodies, να παραγγείλουν μόνα τους, να πληρώσουν. (Γονέας Ο)	I wish there was an organization where I could find support for me and my child. I wish that my child had more opportunities to socialize and develop social skills such as through outings with friends, ordering and paying for a drink. (Parent O)
Parent personal changes	Μέχρι τα 3 έτη χειροτέρευε η κατάσταση και αναγκάστηκα να αφήσω τη δουλειά μου άνευ αποδοχών. Τελικά μας βοήθησε η μητέρα μου οικονομικά και πήραμε και μια δασκάλα που μόλις είχε έρθει από την Αμερική, οπότε ήταν πολύ πιο ενημερωμένη για την παρέμβαση στον αυτισμό. (Γονέας Ρ)	Until the age of three, the situation worsened. As a result, I had to quit my job. My mother helped us financially and we hired a teacher who had just returned from the U.S. and she was informed about offering interventions. (Parent P)
Stigma	Στην αρχή τον φοβόντουσαν. Κάποιοι φίλοι μου όμως δεν τον θέλουν ακόμη. Υπάρχει στίγμα στην οικογένεια. Και ο αδερφός μου δεν τον έχει αποδεχτεί. Δεν τον θέλει. (Γονέας Μ)	Initially, everyone was afraid of him. Some friends of mine do not want anything to do with him. The family is stigmatised. My brother has not accepted him. He wants nothing to do with him. (Parent M)
Social Isolation	Στην αρχή, ήμασταν απομονωμένοι σαν οικογένεια, δεν μπορούσαμε να μείνουμε αρκετή ώρα σε ένα μέρος λόγω των αντιδράσεων του παιδιού μας, βλέποντας τους ανθρώπους να τον	At the beginning, we were isolated as family, we couldn't stay enough time at one place because of our child's reactions, seeing the people to look him strange. Changes in

	κοιτάζουν περίεργα. Οι αλλαγές στην καθημερινότητά του μπορεί να τον αναστατώσουν. (Γονέας Ε)	his routine might be distressing.(Parent E)
Prejudice	Οι άνθρωποι δεν καταλάβαιναν, γιατί δεν βίωναν την κατάστασή μας. Επίσης, φοβήθηκαν πολύ κάποιοι όταν έμαθαν ότι έχω παιδί με αυτισμό. Ακόμη η δασκάλα φοβόταν ότι το παιδί μου θα της κάνει κακό. Φοβόταν ακόμη και να του μιλήσει. (Γονέας Κ)	People did not understand him as they did not share our experiences. Some of our friends were afraid when they found out that I had a child with ASD. Even his teacher was afraid that he was going to hurt her. The teacher was even afraid to speak to my child. (Parent K)

3.7.3 Searching for themes based on the initial coding

Patton (2015) argued that before any process can begin, the researcher has to put away a copy of the raw data for safekeeping and have another for cutting and pasting the data. The copy of the raw data is a key resource for locating information and maintaining the context for the raw data. Brown and Clarke (2006) claimed that one of the important decisions regarding the coding process is the level at which codes are identified. The coding can take place either at a semantic or explicit level, or at a latent or interpretive level. Boyatzis (1998) suggested that coding at a semantic or explicit level indicates the 'visible apparent content of something' (p. 16) while the latter examines the 'underlying ideas assumptions and conceptualizations that are theorized as shaping or informing the semantic content of the data' (pp.83-84).

Moreover, coding at a semantic or explicit level in practice means that the researcher does not search for anything beyond what the participants have said, while coding at an interpretive level allows the researcher to get a better understanding of the situational context. Although Braun and Clark (2006) supported the assumption that the coding process should follow one approach, Boyatzis (1998) pointed out the possibility of taking the 'two levels simultaneously' (p.16), as implemented in this study. According to Braun and Clarke (2006) this step included 'a) code for as many themes and patterns as possible b) code extracts of data inclusively and c) code individual extracts of data in as many themes as they fit due to the fact that no data set is without contradiction. Do not ignore inconsistencies and it is important to retain accounts that depart from the dominant story' (p.19). Patton (1990) suggested that when the researcher starts the analysis, s/he will have two primary sources to look into 'the questions that were gathered during the conceptual phase of the study and clarified prior

to the final analysis and the analytical insights that emerged during data collection' (p.378). Strauss and Corbin (1991) suggested that the coding process is a creative act, that is how building blocks occur and connections between topics begin to appear. The repetitive discussions between the researcher and her supervisor made her realize that it was difficult to separate deciding on a topic or issue from the process of evaluating it. The aim for the researcher was not to only conceptualize but also to examine its adequacy in the light of the data. An example of the codes included in the theme Societal Attitudes and ASD is provided below.

Table 3-5: Searching for themes: An example of the codes included in the theme Societal Attitudes and ASD

Codes	Extracts		Theme
Stigma	Στην αρχή τον φοβόντουσαν. Κάποιοι φίλοι μου όμως δεν τον θέλουν ακόμη. Υπάρχει στίγμα στην οικογένεια. Και ο αδερφός μου δεν τον έχει αποδεχτεί. Δεν τον θέλει. (Γονιός Ν)	Initially everyone was afraid of him. Some of my friends of mine do not want anything to do with him. There is stigma within the family. My brother has not accepted him He wants nothing to do with him.(Parent N)	**Societal Attitudes and ASD**
Emotional Isolation	Ήταν πολύ κουραστικό και ο άντρας μου δεν το άντεχε. Τα πρώτα χρόνια έκανε πολλά πράγματα μόνος του, ενώ εγώ έμενα μέσα στο σπίτι για πολλά χρόνια. Είχα μεγαλύτερη αντοχή και έμενα με το παιδί μου. (Γονιός Α)	It was emotionally exhausting and my husband could not cope with the situation. In the early years, he did a lot on his own and I stayed at home. This pattern lasted many years. I had more stamina and stayed with my child. (Parent A)	
Social Isolation	Όταν ήταν μικρός, επηρεάστηκε η ζωή όλη της οικογένειας. Περάσαμε πολύ δύσκολα. Δεν μπορούσαμε να κάνουμε τίποτα. Πήγαμε διακοπές όλοι μαζί όταν ήταν μεγάλος πια. Ξεκινούσαμε να πάμε βόλτα και αν τον έπιαναν τα νεύρα επιστρέφαμε σπίτι. Ο μεγάλος του αδερφός έκανε παράπονα που έπρεπε μα προσαρμόζεται η ζωή μας στις ανάγκες και τα θέλω του μικρότερου. (Γονιός Q)	When he was a little boy, the whole family's life was influenced by him. We could not do anything. We took vacations only when he was old enough to come with us. If we had a family outing and he had an outburst we had to return home. His older brother complained that we had to adjust our lives in accordance with his wishes. (Parent Q)	

Societal Prejudice	Οι άνθρωποι δεν καταλάβαιναν, γιατί δεν βίωναν την κατάστασή μας. Επίσης, φοβήθηκαν πολύ κάποιοι όταν έμαθαν ότι έχω παιδί με αυτισμό. Ακόμη η δασκάλα φοβόταν ότι το παιδί μου θα της κάνει κακό. Φοβόταν ακόμη και να του μιλήσει.	People did not understand him due to the fact that they did not share our experiences. Some of our friends felt fear when they found out that I had a childwith ASD. Even his teacher was afraid that he is going to hurt her. The teacher was even afraid to speak to my child.	

3.7.4 Review of the themes

When data have been initially coded and a set of potential themes and patterns has been formed, they need to be reexamined to make sure each meets the criteria for inclusion in a theme. Some issues may overlap, so it might be necessary to merge them into one category or to separate others into different themes. Patton (2015) suggested two criteria when examining thematic categories: internal homogeneity and external heterogeneity. In practice, this means that themes should be meaningful and coherent and as a consequence, there should be clear and understandable differentiation between the themes.

Moreover, Tsiolis (2015) argued the quote starts from the word systematically that through thematic analysis, the researcher systematically attempts to detect, organize and understand patterns of meaning (themes) within a set of data and thus to provide cognitive access to experiences (p.13). With this in mind, the third step involved two stages: re-examining and reviewing and improving the themes. The step of reviewing the data had to do with reading the data included in each theme and deciding whether it forms a coherent whole. If the researcher offered a positive answer to this question, then s/he could move on to the second step, which was a similar process, but it referred to the whole data set. The researcher had to decide whether all the research material had been "fully exploited". If not, new codes and topics had to be allocated to the data. Howitt and Cramer (2011) pointed out there were a number of possibilities at this point: there might be very little data related to an identified theme and it needs to be abandoned by the researcher; the researcher might also need to divide data into different themes or subthemes or a new theme might be found; and the applicability of the themes needs to be checked in relation to specific extracts as well as in relation to the entire data set. Miles and Huberman (1994) raised the issue of "convergence". One way to deal with

this is for the researcher to be inductive and systematic. This can be achieved by looking for recurring "regularities". In this way, the researcher can help the reader to see connections. Guba and Lincoln (1985) reminded researchers that the emergence of codes should stop when no new information is generated from the analysis of the data.

In an attempt to enhance the validity of the list of codes used for this study, the researcher asked from her PhD supervisor to read part of the data collected to conduct a "coder reliability check". Her supervisor was also a fluent Greek speaker familiar with the content of the research. This result was the creation of thematic map presented below at the next step of thematic analysis.

3.7.5 Defining and naming themes

The fifth step was taken after the thematic map had been formed. The thematic map includes the following:

1. **ASD Families and Parenting** with the following subthemes:

- 1.1. ASD Parents' Emotional journey "Parents' reaction to ASD diagnosis"
- 1.2. Future outlook for ASD "Parent's Anxiety for the future"
- 1.3. How parents' experiences shaped their world "Parents' Needs" - "Parents' Personal Changes"
- 1.4. Societal Attitudes and ASD "Stigma – Societal Prejudice"- "Emotional – Social Isolation"
- 1.5. Social Support Systems - Societal Intolerance "Social Networks/ Capital > – "Formal and Informal -External Support System"

2. Parents - Professionals Interactions with the following subthemes:

- 2.1. Parent – Professional Working Relationships
- 2.2. Inter-professional collaboration
- 2.3. Parental Involvement /Training programmes
- 2.4. Professionals' attitudes to ASD "Search for ASD professional expertise" - " Professionals' challenges" - Professionals' personal changes

3. SEN Policy and Austerity context in Greece with the following subthemes:

- 3.1. SEN Policy
- 3.2. Structural constraints/Austerity
- 3.3. Political attitudes towards disability “Recognition of children with ASD”
- 3.4. Access to services /Benefits incurred “Systematic Victimisation of parents and children with ASD”
- 3.5. Financial Challenges /Welfare State

In this step the researcher decided each dimension to be included in each theme. S/he must ensure that it is part of the wider discussion and is linked to the research questions of the study. In addition s/he must make certain that there is not much overlap between the themes and subthemes. The themes and subthemes followed the principles of Braun and Clarke’s (2013) systematic guidelines to carrying out thematic analysis can help gain a better understanding of how to organize a large and complex subject. At this stage, the subthemes and thematic patterns should not be one-digit numbers, otherwise further analysis is necessary. Finally, the researcher needed to start considering the labels to give to the issues and topics for the final analysis. Braun and Clarke (2006) suggested that they should be interesting and comprehensive and give the reader a clear understanding of what each heading contains.

Furthermore, Tsiolis (2015) discussing Udo Kelle’s abductive approach to data analysis which was where the researcher approaches the research field with a preliminary conceptual and theoretical framework in mind. The framework changed, expanded and transformed on the basis of the processing of the data. In practice, this means that the researcher could start the coding process having reviewed the literature, with a series of concepts themes or codes in mind. During the coding process, however, the purpose was not to classify data on the basis of preconceived ideas but the transformation of those ideas and the attribution of new parameters would take place through the analytical process. The complete thematic map that emerged presented below:

Figure 3-1: Thematic map: ASD Families and Parenting

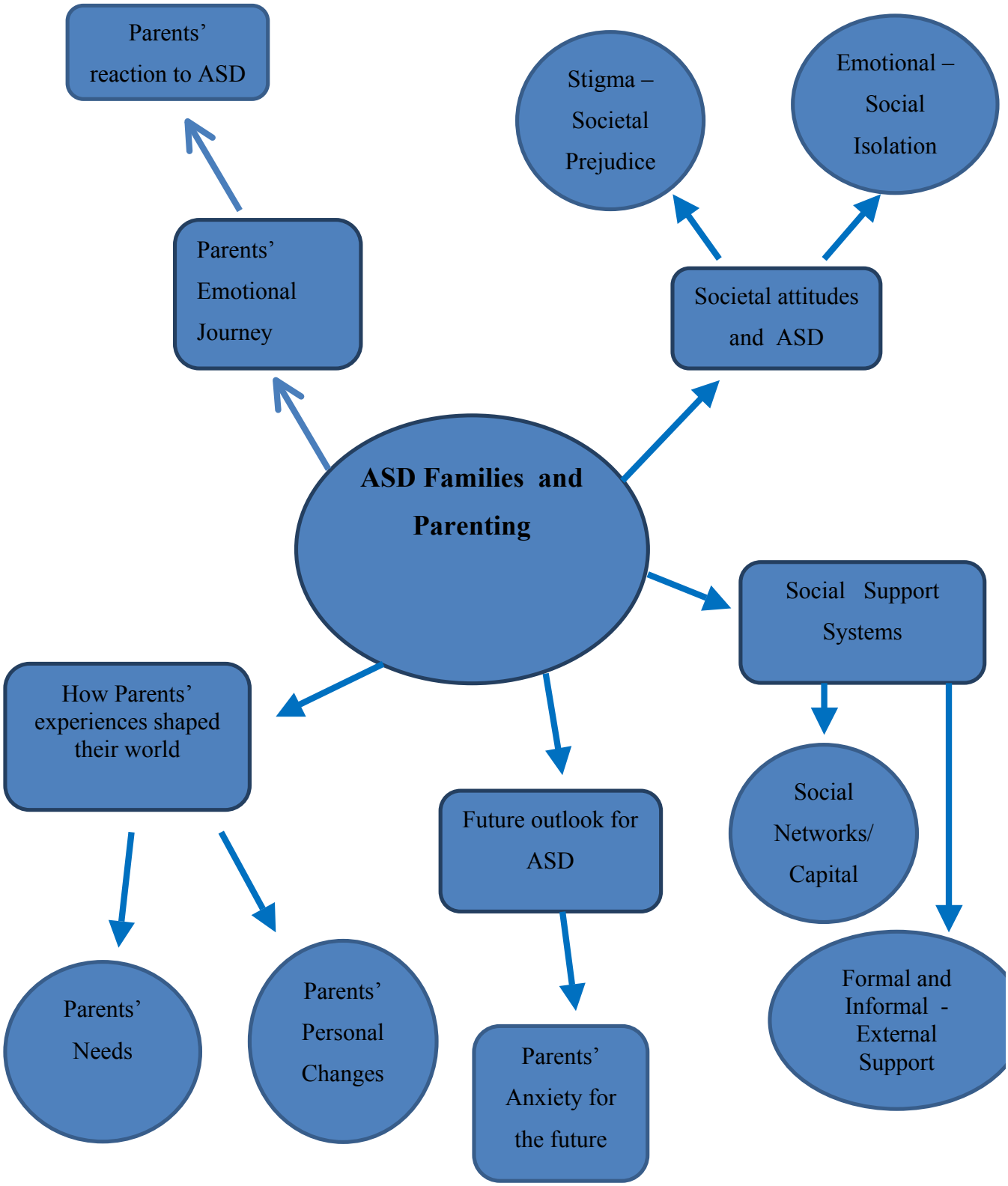


Figure 3-2: Thematic map: Parents –Professionals Interactions

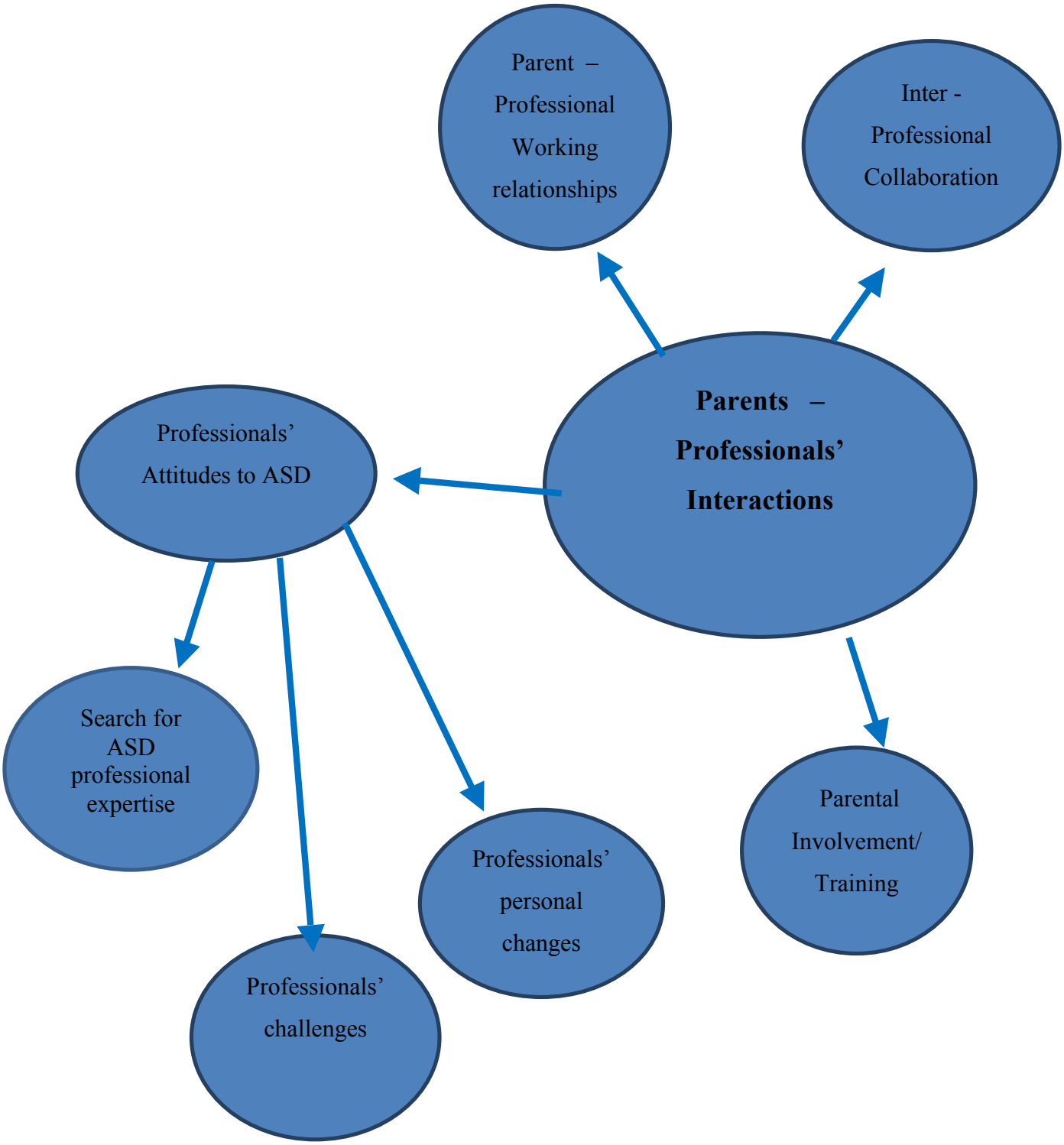
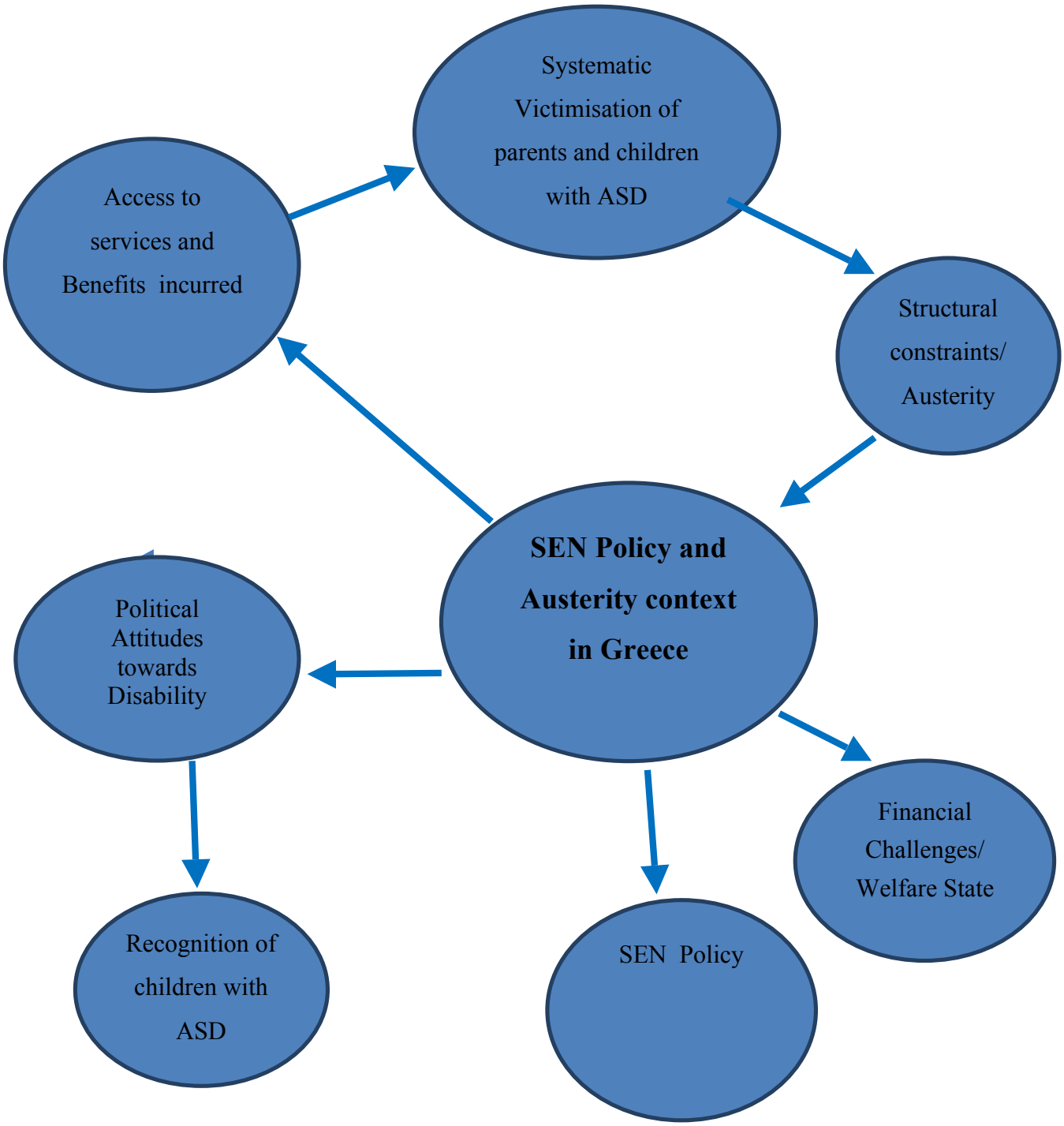


Figure 3-3: Thematic map: SEN Policy and Austerity context in Greece



CHAPTER 4: Presentation of the findings

This chapter is divided into separate sections: the parent views; the professionals' views and the role of State in the Greek educational context. In the first section (parent's views), key issues that parents raised in their interviews are addressed. The second section addressed the views of the professionals. Firstly the characteristics of the sample- interviewees were further clarified then the views of the professionals on different themes regarding their effectiveness, inter professional collaboration and their collaboration with parents followed. In order to further highlight the importance of parent professional interactions, the researcher decided to use data from both the parents' and professionals' interviews. In order to facilitate the management and organisation of data the researcher decided to use a letter of the English alphabet to identify the interview extracts given by parents and those of the professionals by a number. Parental expectations regarding the nature of the collaboration as well as factors that hinder the collaboration between parents and professionals were presented. The final parts of the second section give the professionals' views on the challenges of both a personal and professional nature that they have to deal with. The second section of the findings conclude with presenting the professionals' views of the reasons that hinder the collaboration between parents and professionals.

The final section of this chapter discusses the role of the state in supporting families with ASD children. The views of parents and professionals were presented jointly in order to strengthen the argument presented and make clear the points of view of two equal partners on a number of issues given the financial crisis that Greece has experienced.

4.1 Parents' views

74 parents of children with ASD completed a survey addressing a number of issues related to ASD. 20 of the 74 parents went on to further discuss with the researcher their way of dealing with their child's needs. The demographic characteristics of the sample showed that the majority were mothers 70.3% who had basic education 47.3% and 85.1%were married.29.7% were fathers, with 8.1% being divorced, 5.4% widowed and 1.4% single. Regarding education, 47.3% of the parents

were lyceum graduates and 35.1% university graduates with 14.9% having a Masters or a PhD degree. A small percentage (1.4%) were primary and high school graduates. Over half of the parents stated that they did not have a sibling with ASD (60.3%), but the rest of them did have a sibling with ASD. Over a quarter of the children (27%) were first diagnosed with ASD at the age of 3, 78.4% being boys and 21.6% girls.

Parents were also asked if their child with ASD presented any medical issues. Over two thirds of the children with ASD had language and speech problems (70%) nearly a quarter (18.3%) reported balance and coordination problems and a small percentage (5%) had hearing problems. Less than a third of the children had feeding problems (30%), a quarter presented clumsiness and a small percentage of children (12.2%) reported other problems (e.g., hypothyroidism, Crohn's disease and gastro esophageal regression).

4.1.1 Parents' challenges

Parents who participated in this study suggested that one of the challenges they face was their inability to understand their child's behaviour and thus predict or interpret his/her reactions. This in turn negatively influenced the family as a whole since it was difficult for effective support to be found. The following extracts highlight the ideas suggested above:

"The challenges in our everyday life were a lot. One of the biggest difficulties was to communicate with my child, to understand why children with ASD fixate on insignificant things. When my child can't talk to express himself it is very difficult to predict something such as his competences" (Parent A).

"Autism was a big obstacle. We have not kept our child at home and we struggled to overcome his daily difficulties. Definitely, it was a barrier to the structure of our family because it was something that my child had to tackle. It was a real challenge to help our child" (Parent M).

The first issue raised in the area of family needs and emotional challenges related to the range of emotions experienced by parents when their children were diagnosed with ASD. These were summarised in six main categories such as: **Fear** (shock, terror), **Anxiety** (denial, confusion, impaired concentration, uncertainty, helplessness), **Worry**

(sadness, guilt, loneliness), **Defea**t (frustration, irritability, anger), **Self Confidence** (decreased self-esteem, decreased self-efficacy) and **Positivity** (acceptance, hope). Specifically, over half of the parents experienced worry, anxiety and defeat repeatedly after receiving the diagnosis of ASD for their child. A third of them experienced fear and positivity and one out of four parents did not feel self-confident .The responses are presented below (Table 4-1):

Table 4-1: Percentage (%) of Parents' reactions towards ASD diagnosis

Emotions	Never- Almost Never	Sometimes	Often - Very Often
Worry	1.6	23.1	74.2
Anxiety	7	24.1	67.8
Positivity	2.8	30	67.2
Defeat	7.1	26.3	66.6
Lack of Self-Confidence	24.1	20.7	55.2

An independent T-test was conducted to examine gender and education differences in parents' reported feelings and reactions to the diagnosis of ASD. Weak yet significant differences between mothers and fathers were found regarding anxiety[t(52)=2.77, p.008, d.10]; worry[t(52)=5.53, p.000, d.25]; defeat[t(52)=4.83, p.000, d.10]; and self-confidence [t(52)=2.97, p.004, d.17], showing that mothers were more likely to express anxiety, worry, defeat and self-confidence more often than fathers. There were no statistically significant differences regarding the frequency of parental reaction towards ASD as a function of their education level (see Table 4-2).

Table 4-2: Parents' reactions towards ASD diagnosis Compared Means/Independent

	M(SD)	M(SD)	T	M(SD)	M(SD)	T
	Mother	Father		Compulsory Education	Higher Education	
Fear	2.66(1.28)	2.16(1.17)	1.42	2.52 (1.32)	2.53(1.21)	.01
Anxiety	3.12(.957)	2.40(.75)	2.77* (d=.83)	2.93(.97)	2.86(.95)	.27
Worry	5.56(1.65)	3.19(.97)	5.53* (d=1.82)	4.95(1.88)	4.86(1.81)	.19

Defeat	5.12(2.10)	2.56(1.11)	4.83* (d=1.52)	4.35(2.23)	4.22(2.19)	.21
Self confidence	2.86(1.32)	1.78(.93)	2.97* (d=.94)	2.57(1.33)	2.52(1.30)	.16
Positivity	2.80(.922)	2.52(.76)	1.20	2.65(.88)	2.79(.88)	.63

*p<.05 **p<.01 *** p<.001
N= 16 – 52 N= 16 – 52

Parents of children with ASD experienced a range of feelings and a set of challenges that had an impact upon their psychological adjustment. Specifically, they experienced feelings ranging from sadness and disbelief, to loss. In their interviews, they talked about pain, sadness and despair as well as about their determination to make the necessary changes in order to help their children. These are expressed below:

"You pass from denial to unawareness. Sadness, anger and sorrow overwhelm you". She experienced disbelief, irritation, denial, anger and finally acceptance" (Parent P).

"Our emotions were simple; Unhappiness and devastation. On the other hand, we were determined to help our child. I try to read and make some changes in order to help my child and respond to his needs" (Parent S).

Parents in this study were afraid due to lack of knowledge about professional guidance for their children. They also were very clear about an overall lack of professional support regarding their child's condition that contributed to their sense of helplessness. The results are presented below:

"The emotion that I felt was totally unknown. It was something really strange. I didn't know where to look for information, and I couldn't think what books I should read in order to get some extra help. I shared my concerns with my family. I started looking for diagnostic centers and clubs, without knowing anyone with children with ASD to guide me. My family couldn't help me at all. I also appealed to the Center for Differential Diagnosis, Diagnosis and Support (K.E.D.D.Y.) where the specialists gave me some help" (Parent I).

"At first, we felt afraid, we were worried, we were totally ignorant. We had the diagnosis but we didn't know anything about ASD because nobody explained to us what

it is. Of course, we knew very well that each child is different but we scoured the Internet and our inner circle in order to find some more information about ASD. We also tried to ask for information from some experts. The first emotions were sadness and ignorance" (Parent R).

In terms of parents' challenges, over half reported they had difficulty in dealing with their children's language, communication and social skills deficits. Around half expressed concerns about their children's self-help skills whereas around a third did not report any challenges in this area. Further, less than half of them had problems dealing with difficult behaviour, recreational difficulties and the need to follow routines. Furthermore, around a quarter agreed that their motor skills are challenging (see Table 4-3).

Table 4-3: Percentage (%) of Parents facing autism related challenges

Parents have dealt with the following behaviours	Disagree/ Strongly disagree	Neither agree or disagree	Agree/ Strongly agree
Poor language, communication and social skills (interacting with family and community)	24.3	24.3	51.4
Poor self-help skills (eating, dressing)	31.8	27.3	40.9
Recreational difficulties	28.4	32.8	38.8
Behaviours that challenge (odd mannerisms, stereotypical behaviour)	26.4	37.5	36.1
Strict compliance to routine including excessive ritualistic behaviour	40	24.6	35.4
Poor motor-skills	36.9	35.4	27.7

In general, there were no education or gender differences in parents' ratings of the challenges experienced as a result of having a child with ASD. However, a moderate statistically significant difference was found regarding the difficulty in dealing with ASD related behaviours such as odd mannerisms and stereotypical behaviours [t (52) =0.07, p.047, d.53]. Compared to fathers, mothers were more likely to experience

difficulties in dealing with such behaviours (see Table 4-4). Irrespective of education and gender, the parents of children with ASD experienced roughly equal challenges.

Table 4-4: Autism related challenges by gender/education

	M(SD)	M(SD)	t	M(SD)	M(SD)	T
Relationship	**Mother**	**Father**		**Compulsory Education**	**Higher Education**	
Behaviour Deficits	2.35(.79)	2.05(.91)	.81	2.11(.83)	2.43(.81)	.01
N	51	19		35	35	
Behaviour Challenges	2.21(.77)	1.80(.76)	.07* (d=53)	2.06(.79)	2.14(.79)	.14
N	52	20		36	36	
Deficits in self-help skills	2.04(.84)	2.22(.87)	.25	2.06(.85)	2.13(.87)	.20
N	48	18		34	32	

4.2 Future outlook for ASD

4.2.1 Parent's anxiety about the future

It became clear from their statements that parents were overcome with fear and stress about the future of their children. Parents worried about how the condition of their children was likely to hinder their coping mechanisms as parents. Also, they were worried about the influence that ASD is likely to have on siblings and were anxious about the situation after they, the prime caretakers, pass on. Parents seemed to be full of hope and at the same time despair about the independence, autonomy, and dignity of their children with ASD in the future. The following quotes highlight the ideas suggested above.

Parent H reported: *"As I grow older, one of my greatest fears is not to destroy my other children's lives. I don't want my other children to feel that they are obliged to look after their brother with ASD. I hope my child with ASD will shape his own character and manage to be independent too".*

Parent F stated: *"I am experiencing a lot of stress. I would like to live as many years as I can in order to protect my child. There are no public structures which can ensure that she will spend the rest of her life with dignity".*

Parent C stated: "*I wanted my child with ASD to be independent, especially in the bathroom. I am trying not to look too far into the future. I don't know what will happen in the future so I must stop feeling sorry for something that is already a fact. I'm trying to concentrate on short-term goals in order to succeed. "*

Parent R wondered*: "Will he be able to look after himself or to take care of his younger sister? What will happen if he faces emotional failure, rejection by his friends or loneliness? Will he be able to handle the money that he gets from the social welfare to fulfill all his needs? Will he live in his own house? How will it be this? I don't know what will happen in the future."*

Parent S reported: *"I am experiencing so much anxiety and stress concerning my child's future. Will he be able to cope with the difficulties in our society? Will he manage to live as an independent and autonomous member?"*

4.2.2 How parents' experiences shaped their world

Parents who participated in this study indicated that after the initial sock of the diagnosis they had to meet the medical as well as educational needs of their children. Such a situation brought to the foreground financial difficulties due to loss of earnings and job security. Moreover, the participants talked about to the need to adapt and this absorbed their time and as a result, made it difficult for them to allocate time for the fulfillment of their personal needs. Indeed, half of the participants in this study claimed that they had made changes in their lives personally and professionally in order to accommodate their children's needs (see Table 4-5).

Table 4-5: Parents' personal changes

	Yes	**No**
Changes you made in your life in order to accommodate your child's needs	52%	48%
Changes you made in your professional life in order to accommodate your child's needs	52.1%	47.9%
N=74		

Moreover, the participants indicated in their interviews that dealing with their child's condition made them experience changes in their personalities, making them

more tolerant stronger and more humane in their approach to others. At the same time, the participants suggested that the changes they had experienced were intense and influenced all aspects of their lives. The following quotes illustrate the ideas suggested above:

"It was a real slap for us. Our selfishness became reduced, our patience increased and our nerves tensed up. Now, I'm more patient and restrained too. This story made me wiser. I'm more generous than I used to be in the past." (Parent J).

"As a parent of a child with ASD, I experienced problems that brought pressure on my family. My life changed at all levels, towards my child, other children, myself, and my husband. Everything changed." (Parent D)

4.2.3 Perceived impact of ASD on family relationships

Parents were asked about the extent to which caring for a child with ASD had affected their relationship with their spouse. Half reported there it had made a severe impact whereas the other half reported only a slight impact. Likewise, more than half reported an important impact on their relationships with their extended family. Their social networking was also be affected, claimed half the parents. In terms of the effect that their child with ASD had on the arrival of another child, more than half of the parents stated that there was a great effect while a quarter stated that it had little effect. Furthermore, regarding the influence that the ASD child had on the quality of their siblings' lives, more than half of the participants claimed that this had been important. The vast majority of parents stressed that the autistic child had a great effect on the financial situation of the family (see Table 4-6).

Table 4-6: Percentage (%) of parents rating of perceived impact

	Mild Impact	Severe Impact
Financial situation of family	24.3	75.7
Social networking	37.0	63.0
Arrival of a new child in the family	37.3	62.7
Quality of other children's lives	38.0	62.0
Relationships with relatives	38.9	61.1
Relationship with spouses	47.9	52.1

There were no education and gender differences and parents across education levels perceived the impact of ASD on the family, in that mothers and fathers responded similarly to this survey probe. However, a modest difference was found between mothers and fathers [t (52)=0.14, p.04, d.50], with mothers perceiving the impact of ASD child on family finances to be greater (see Table 4-7).

Table 4-7: Impact on family by gender/education

	M(SD)	M(SD)	T	M(SD)	M(SD)	T
	Mother	**Father**		**Compulsory Education**	**Higher Education**	
Relationship with spouse	1.94 (.83)	1.71 (.86)	.96	1.86(.89)	1.89(.93)	.47
Relationships with relatives	1.96(.89)	2.05(.86)	.37	1.89(.85)	2.08(.90)	.64
Social networking	2.17(.90)	1.90(.94)	.15	2.11(.88)	2.08(.95)	1.69
Arrival of a new child in the family	2.13(.93)	2.00(.89)	1.31	2.21(.88)	1.97(.95)	1.11
Quality of other children's lives	2.06(.85)	1.73(.82)	.0	2.00(.86)	1.91(.85)	.00
Financial situation of family	2.52(.82)	2.09(.86)	.14* (d=50)	2.46(.86)	2.32(.85)	.00

*p<.05 **p<.01 *** p<.001
N= 21- 52 N= 33 -37

4.2.4 Family adjustment process: Siblings-marital relationship-working life

Interviewees said that their children were their key priority. They acknowledged secondary stressors influenced their life, specifically, parents admitted that they had to forgo earnings because they either were unable to find flexible employment or because they had to work fewer hours. Moreover, the participants suggested that siblings in the family experienced feelings of guilt and shame while the situation has strongly influenced marital relationships. The following quotes reflect these points:

"Our life has changed dramatically, our programme has changed. We all revolve around our son. Our aim is to help him. We strive to help him participate in activities, and not to be excluded from anything" (Parent F).

"One of our biggest problems is that his older brother feels guilty and shame simultaneously. Recently, they have started doing sessions together and he is not negative" (Parent N).

"The challenges that we face in practical, emotional and financial terms have created many problems. The relationship with my husband has been turbulent. He is a great father, but frustrated too. At first, he cut himself off because of his son. In the beginning he could not bear the diagnosis, he wanted to leave. When you have a child with ASD, it is difficult to understand whether you're with the dad because you really love him or because you have this child and you should carry the burden together. Finding that out, takes many years of hard work. It has also affected our social life" (Parent H).

"Firstly there is no free time for us and secondly we 're still unemployed, we can't look properly for work. When we need to pick up my child from school at a certain time, even if someone could get me an interview, my mind must be continually on my child. It is a serious problem finding a job and there is no time to take a breather" (Parent D).

4.2.5 Coping strategies and practical constraints

The participants in this study clearly indicated there was a lack of support from the state in their attempt to deal with the difficulties that arose from their child's condition. They highlighted the need for psychological support for themselves as well as educational support for their child. At the same time, the majority also acknowledged the fact that their child's ASD was unique in every case. This led some of the participants to become skilled in dealing ASD by necessity. The family unit alongside the extended family contributed a significant amount of emotional and practical support to the parents.

"Our kid has been supported by our relatives and us. If everyone doesn't work together, every individual effort seems to be useless. Eventually, people who are next to my child are more special than anybody else. Autism is something very intense and continuous, so the family needs a lot of strength to pull through. Unfortunately, the state cannot offer enough support. The most significant factor in dealing with ASD is communication between the parents. Parents are specialists more in ASD more than in any other disorder, because they are experienced and live with it"(Parent O).

"I need a lot of help for my child and myself. I think that psychological support and special educational help in regard to our child's needs, is really important. We have no free time because we are always busy and our life is a muddle" (Parent E).

I try to teach him by experience. When he has a tantrum, if he can understand how I feel and he can change his behaviour. So, I try to show him that I'm not feeling well and we try to reach an agreement" (Parent Q).

Furthermore difficulties in collecting a welfare allowance were acknowledged by fourteen out of the twenty parents.

"Parents face a lot of problems. Parents have problems even with the procedures that are followed, such as the welfare allowance, which takes a lot of time and is difficult. First, they must apply to a public hospital to get the diagnosis, and then they have to go to the Disability Certification Centre (KEPA) and in particular, to the health service, which is held every three to four years until the child reaches adulthood. Parents also have various practical problems with the doctors who monitor their children. Generally, bureaucracy is very tiring" (Professional 26).

4.3 Societal attitudes to ASD and disability

The participants in this study indicated that for them, their relationship with the world involved indifference or compassion, and the need to explain the inexplicable behaviour of their child. The interviewees indicated that society's attitude toward ASD is influenced by prejudice and stigma. The professionals acknowledged that society's attitude towards autism needs to be more open and sensitive to individuals with disability.The negative consequences of social stigma demonstrate themselves in the form of isolation and discrimination at the expense of a child with ASD. The following quotes reflect this:

Parent F experienced prejudice: *"I experienced my child's stigma in a private kindergarten. It was the first slap. I experienced racism, when the teacher told me that my child would not participate in the school's celebration because the other parents*

would be concerned. I tried to protect my child. I moved him to a public kindergarten where the environment was more appropriate because the teachers accepted him. I did everything to forestall the difficulties and the other parents' reactions at that school".

Parents G and H (a married couple) explained: *"We experienced prejudice when our child studied at a special school which cooperated with a mainstream school. Some of the parents whose children were at the mainstream schools thought that my child should stay to in a special school without communicating with the children of the mainstream school. During break time, many children moved from the special school into schoolyard of the mainstream school without socializing with other, normal children. This was a stigma".*

"I believe that people are more sensitive for disabled people than in the past and there is a progress. I believe that younger teachers are more informed about the disability than the older ones" (Professional 12).

"We should understand that disability is part of our lives; teachers should understand this as well. This is what I tell them: there should not be the 'Oh! The poor child' approach. Children with special needs and especially those in the autism spectrum, are the children in our schools and our society. A child who is a pupil now, in some years' time he/she may be my children's colleague. So, we must learn to tackle and know how to manage these kinds of issues" (Professional 4).

"In the age of austerity, the disability is afflicted. These kinds of groups are afflicted in austerity programs because they have the weakest voice" (Professional N).

As shown in Table 4-8, around half of the parents reported negative stereotyping and prejudice, with more than half considering public awareness of ASD to be low. Less than half reported having encountered social stigma because their child was perceived as 'disobedient'. Most parents faced challenging behaviours (e.g. aggression, tantrums, stereotypical behaviours, self-injury, socially inappropriate behaviour, being withdrawn) while only 13 out of 100 parents reporting no such challenges.

Table 4-8: Social stigma

	Yes	No
Low public awareness of ASD	64.9	35.1
Prejudice	56.8	43.2
Stereotyping	48.6	51.4
Society labeling the child as 'disobedient;	36.5	63.5
Bullying	18.9	81.1
No challenges	12.2	87.8

4.4 Social support system /Societal Intolerance

4.4.1 Social – Emotional Isolation and Social Networks/Capital

Due to the difficulties experienced in terms of communication and social interaction children with autism exhibit behaviours that are disruptive and hard to manage. Such behaviours are not only a source of stress for parents but also make them feel extremely isolated. According to the interviewees' responses, the social environment often poses control and discipline issues for children with ASD and their families. Parents experienced negative comments and rejection by the social environment due to their children's behavior, especially when outside, in situations involving contact with other people in public places such as the church, playground, restaurants or shops. Parents reported that they faced a lot of social challenges in order to have a normal social life.

"At the beginning, we were isolated as a family; we couldn't stay long enough in one place because of our child's reactions, seeing people looking at him strangely. Changes in his routine could be distressful" (Parent Q).

"Sometimes, I feel gross injustice because people don't understand, and they don't accept my child's particularity" (Parent E).

The majority of parents experienced isolation due to their children's reactions, in a social environment. The majority mentioned that it is necessary to create a social network of parents with children with ASD to exchange ideas and experiences in order to help each other. Sharing their opinions and experiences in an environment that is

friendly to their child might be a way forward. The following extracts illustrate the ideas suggested above:

"Parents of children with ASD support a café, <Myrtilos>, in a northern suburb of Athens which some other parents set up. Their high functioning children with ASD work there and it is a very good opportunity for our children to meet and to develop a social network" (Parents C and K).

"We share our experiences with our social environment because we want to include our child. We believe that it will be really helpful for him to be a member of society" (Parent O).

The interviewees acknowledged that emotional care of their children with ASD could be given by other persons who are close to them. Some of them externalized their feelings to their extended family, and friends who also were parents of children with autism. Strong coping skills and informal support are needed by parents with autistic children in order to reduce stress and deal with the intense effects of the disease on their child.

"I externalize my thoughts and I talk about them with my husband, my mother or my friends. I want to externalise my concerns, I can't keep them hidden. I want to externalise my unhappiness and the thoughts that ail me. After being relieved, I see things a bit differently. I can have another perspective, and that gives me a lot of courage to go on. As a parent I have to try hard in order to overcome the difficulties, without caring what others say" (Parent G).

"I think that all of us need emotional care. So, those who try to use their positive energy, their good mood, their knowledge and their feelings really help my son. His teachers at the special school, his brothers and our relatives treat him like this. They spend time to educate or make him feel good and this covers us emotionally"(Parent L).

The responses of the interviewees in this study clearly indicate the need for a supportive external network for them and their children. The suggestions made by parents indicate their hope to find support in Parents' clubs, Church clubs, Parents'

Group Therapy Clubs or in organizations such as the Greek Autistic Association or the ASD Federation.

"I have contact with other families and share opinions and common experiences with them. As an "older parent", I provide them with help and I try to advise them what to do or where to go. The Federation consists of many Parents' clubs all over Greece" (Parent M).

"The understanding of the social environment for my child is fundamental. Furthermore, the Church can help children with ASD to create teams. It could gather local people and ask them to work as volunteers. People with free time could learn about the ASD children's needs. I wanted to have a group of volunteers from the municipality or the church to take care of people with ASD who may live alone or have feeding problems " (Parent S).

4.4.2 Extended Family Support

Parents who participated in this study looked for support outside the nuclear family Grandparents, friends and in laws can be a valuable source of social support, allowing parents greater flexibility to meet their family's needs. The extended family with grandparents has always played an important role within Greek culture. The extended family can be regarded as a social network and a source of practical and emotional support through quality interaction. The extended family can provide a helping hand for parents while at the same time, it can help strengthen their beliefs so that they can manage the difficulties they face, overcome their fears and move on.

"My family environment supported me very much. I had psychological support from my husband, he always thought positively. When I saw everything as black, I didn't know how to fight, but I have always externalized my pain by discussing my child's troubles with my friends" (Parent A).

"Our mother played a supportive role by helping us when our child was young. At the beginning, there were the comforting words that everything would be fine. In Greece, where the state is absent, there is always the grandmother"(Parents O and E).

"At first, we didn't say anything to the extended family because we did not know what ASD was. People in our family did not understand, so we avoided talking to them about it. We did share our problem with my parents and my grandparents, who are closer to my child" (Parent F).

4.4.3 Family needs and systems of support

More than half of parents rated support with educational decisions, child development, finances matters and access to public services as very important. Concerning discussing feelings, the parents of ASD children and needed reassurance to avoid having negative feelings about a child's unusual behaviours, parents were equally divided into those who rated this as important or slightly important. Around half of parents rated counselling as important for them and their spouse and this need was being partly met for less than half of the parents. Most parents rated developing a social network as very important but half did not have access to such a network. More than half of parents stressed that their need for support for educational decisions and decisions about the level of autonomy for ASD children, were only partly met. Finally, the need for help in the care and positive handling of parents' problems was met for two thirds of them (see Table 4-9).

Table 4-9: Percentage (%) of parents rating needs and the extent to which these were met

Parents needs	Not Important/ Slightly Important	Important	Very important	Unmet	Partly Met	Met
Financial support	8.1	17.6	74.3	23.6	54.2	22.2
Educational decisions about the child	2.7	28.4	68.9	12.7	62.0	25.4
Support concerning the autonomy of the child	4.1	27.0	68.9	16.7	61.1	22.2
Assistance from public centers (K.E.D.D.Y., medical centers)	9.5	25.7	64.9	20.8	50.0	29.2

Help in care and positive handling of problems	9.5	35.1	55.4	23.6	44.4	31.9
Access to counselling	17.6	33.8	48.6	26.8	40.8	32.4
Social networking	17.8	41.1	41.1	52.1	38.0	9.9
Reassurance regarding negative feelings about child's unusual behaviours	39.2	40.5	20.3	39.4	54.9	5.6
Discuss feelings with other parents	40.5	40.5	18.9	29.6	52.1	18.3

There were no gender differences in the ratings of the importance of support between mothers and fathers. However, a strong statistical difference was found regarding parents' ratings of the importance of assurance regarding their having negative feelings about a child's unusual behaviours [t (52) =0.16, p.002, d.84]. Compared to fathers, mothers were more likely to rate their need for reassurance highly. There were no statistically significant differences between mothers and fathers and education groups regarding parents' ratings of the importance of having support. However, a moderate statistical difference was found regarding parental rating of the importance of emotional support from other parents of ASD children [t(52)=0.11, p.02, d.52]. Parents who have completed only compulsory education rated the importance of emotional support from other parents more highly than those with a higher education background (see Table 4-10).

Table 4-10: Parents' ratings of support by gender and education

	M(SD)	**M(SD)**	**t**	**M(SD)**	**M(SD)**	**t**
Help with:	**Mother**	**Father**		**Compulsory Education**	**Higher Education**	
Family members	2.46(.69)	2.45(.59)	1.11	2.59(.55)	2.32(.74)	5.56
Educational decisions	2.71(.49)	2.55(.59)	3.27	2.57(.55)	2.76(.49)	4.97(.36)
Autonomy support	2.69(.57)	2.55(.51)	0.21	2.62(.54)	2.68(.58)	0.07

Emotional support	1.81(.76)	1.73(.70)	0.34	1.97(.76)	1.59(.68)	0.11* (d=52)
Reassurance	1.98(.75)	1.41(.59)	.16* (d=84)	1.81(.77)	1.81(.73)	0.22
Counselling	2.35(.76)	2.23(.75)	0.27	2.30(.77)	2.32(.74)	0.10
Social network	2.29(.78)	2.09(.61)	8.29	2.31(.66)	2.16(.80)	1.37
Financial matters	2.71(.57)	2.55(.73)	3.65	2.76(.43)	2.57(.76)	11.31
Public centres	2.56(.698)	2.55(.596)	0.503	2.59(.55)	2.51(.76)	4.62

*p<.05 **p<.01 *** p<.001
N= 22-52 N = 36 -37

4.5 Summary

The parents of children with ASD experienced a range of feelings; they particularly worry about their future in terms of achieving an independent life. ASD was thought to influence every aspect of the parents' and family lives, requiring readjustment in their personal and professional lives and priorities. The existence of both professional and family networks was crucial for supporting the parents of children with ASD to tackle prejudice and stigma.

The statistically significant relationships between variables that emerged from the quantitative analysis showed that mothers who have a child with ASD expressed higher levels of worry, anxiety and a greater sense of defeat than fathers. Also, mothers experienced more difficulties in dealing with ASD behaviour deficits and they needed more reassurance to cope with their negative feelings about their child's unusual behaviours than did fathers. Furthermore, mothers perceived the impact of their child on the family finances as being severe. Parents with only compulsory education levels were more likely to need emotional support from other parents with children with ASD than parents with higher education levels.

4.5.1 Key Findings of Parents' views by gender

Parents' reactions to ASD diagnosis	**Mother**	**Father**	**T**

Anxiety	3.12(.957)	2.40(.75)	2.77* [t(52)=2.77, p.008, d.10]
Worry	5.56(1.65)	3.19(.97)	5.53* [t(52)=5.53, p.000, d.25]
Sense of Defeat	5.12(2.10)	2.56(1.11)	4.83* [t(52)=4.83, p.000, d.10]
Self confidence	2.86(1.32)	1.78(.93)	2.97* [t(52)=2.97, p.004, d.17]
Autism related challenges	**Mother**	**Father**	**T**
Behavioural Challenges	2.21(.77)	1.80(.76)	0.07* [t (52) =0.07, p.047, d.53]
Impact on family	**Mother**	**Father**	**T**
Financial situation of family	2.52(.82)	2.09(.86)	0.14* [t (52)=0.14, p.04, d.50]

4.5.2 Key Findings of Parents' views by gender and education

Parents' ratings of support	**Mother**	**Father**	**T**	**Compulsory Education**	**Higher Education**	**T**
Emotional support	1.81(.76)	1.73(.70)	0.34	1.97(.76)	1.59(.68)	0.11* [t(52)=00. 11, p.02, d.52]
Reassurance	1.98(.75)	1.41(.59)	0.16* [t (52) =0.16, p.002, d.84]	1.81(.77)	1.81(.73)	0.22
Parents' perceived usefulness of remedial services	**Mother**	**Father**	**T**	**Compulsory Education**	**Higher Education**	**T**
Sensory Integration	1.60(.70)	1.50(.67)	0.24	1.47(.69)	1.68(.68)	0.24* [t(52)=0. 24, p.03, d.30]

4.6 Presentation of professionals' views

In this section, professionals' views are presented. 140 professionals completed a questionnaire concerning various aspects of their work with children with ASD and their parents. In addition, 40 professionals were interviewed by the researcher to discover how the professionals dealt with the issues arising from working with ADS

children and their parents. The findings in this section are presented under the following themes: parents' – professionals' interactions, parents' – professionals' working relationships, inter-professional collaboration, search for ASD professional expertise, professionals' work challenges and professionals' personal challenges respectively.

4.6.1 Demographic Characteristics of Professionals

The majority of the professionals who participated in this study were female (63.5%) with less than 10 years of work experience. 36.5% were male; over half (62.2%) had a university level qualification and one third (37.8%) had high school education level. Specifically, 21.6% of the professionals were T.E.I. (College) graduates and 40.5% university graduates, 33.8% having a Master's degree and 4.1% a PhD. In terms of their work experience, the majority of the professionals (70.3%) had less than 10 years, 27% had between 10 and 15 years work experience and the rest (2.7%) had more than 15 years.At the same time, all the professionals declared they had an area of specialization, while the majority worked in K.E.D.D.Y. (Centers for Differential Diagnosis and Support of Special Educational Needs) with children aged between 7-12 years. Finally, participants in this study were very clear as to what their most important duties involved. 31.8% were SEN teachers a quarter were Special Educators (25%), 10.8% were Speech and Language Therapists, a small percentage (8.1%) were Educational Psychologists and Social Workers, (5.4%) were Occupational Therapists, 3.4% were Clinical Psychologists and Children's Psychiatrists and the remainder (2%) were Counselling Psychologists and Music Therapists. The results are presented below (Table 4-11).

Table 4-11: Area of specialization

PROFESSIONALS	PARTICIPATION RATE
SEN Teachers	31.8%
Special Educators (in centres)	25%
Speech and language therapists	10.8%
Educational Psychologists and social workers	8.1%
Occupational Therapists	5.4%
Clinical Psychologist and Children's Psychiatrists	3.4%
Counseling Psychologist and Music Therapists	2%

The majority of professionals (48.6%) worked with children with SEN. One out of five professionals (20.9%) worked in K.E.D.D.Y. (Centres for Differential Diagnosis and Support of Special Educational Needs),11.5% worked in Autism Specific Education, 9.5% worked in Mental Health Centres, 5.4% worked in mainstream education and 4.1% were involved in Day Care Centres which offer mental health services to children and adolescents diagnosed with ASD (see Table 4-12).

Table 4-12: Professionals' work place

PROFESSIONALS' WORK PLACE	PARTICIPATION RATE
K.E.D.D.Y.	20.9%
S.E.N.	48.6%
Autism Specific Education	11.5%
Mental Health Centres	5.4%
Day Care Centres	4.1%

The majority of professionals worked with groups of students aged between 7 and 12 years old, 27.7% worked with those aged between 13 and 18 years old, a small percentage of them (14.9%) worked with those aged 0-6 years, 12.2% worked with students of all ages while only 3.4% worked with students over 18 years of age (see Table 4-13).

Table 4-13 : Age Group of Children

CHILDRENS' AGE	PARTICIPATION RATE
0-6 Years	14.9%
7-12 Years	41.8%
13-18 Years	27.7%
Over 18 Years	3.4%
All age groups	12.2%

Regarding the nature of their work, more than half of the professionals reported that they had diagnosed children with ASD, around two third (58.8%) did counselling work and met the individual needs of children with ASD, half of them reported that they dealt with teaching, 41.9% made assessments and 35.1% had developed individual education programs (IEP) for ASD children (Table 4-14).

Table 4-14: Main Duties of Professionals

PROFESSIONALS' DUTIES	PARTICIPATION RATE
Diagnosing children with ASD	60%

Counselling, meeting children's individual needs	58.8%
Teaching children with ASD	50%
Carrying out Assessments	41.9%
Developing IEP for children with ASD	35.1%

Furthermore, the participants in this study seemed to be especially interested in strengthening their professional profiles. Their way of achieving this was through attending special interest seminars. Most professionals stated that they had attended ASD training to help them in their job. Specifically, more than half had attended a seminar entitled: 'Introduction to Autism' and 'Sensory Needs' and one in four a seminar on 'Behaviour and Communication'. Two thirds of the professionals stated that they had participated in ASD training of up to 50 hours, one in five professionals had participated in seminars lasting between 10 and 30 hours and the remainder (14.4%) had participated in seminars of between 30 and 50 hours. Half of the professionals (52.2%) reported that they had attended up to 30 hours of training seminars and around half (47.8%) had attended between 31 and 60 hours. Regarding ASD training programmes, over half of the professionals reported that the training on 'Advice about individual student's social and communication needs' was beneficial for them. Furthermore, half stated that the training programmes entitled: 'Educating ASD children', 'Adapting policies and procedures' and 'Auditing of the environment to be more autism-friendly' had been interesting and beneficial (Table 4-15).

Table 4-15: Percentage (%) of Professionals' perceived benefits of ASD training programmes

Training Programmes	**Yes**	**No**
Advice about individual student's social and communication needs	73.1	26.2
Educating children with ASD	59.7	40.3
Adapting policies and procedures	52.8	47.2
Auditing of the environment to be more autism-friendly	52.4	47.6
Working in partnership with families	47.9	52.1
Hearing direct school experiences from those with autism	25.5	74.5
Tailored workshops for supporting particular students	10.4	89.6

Using cross-tabulation to analyze the relationship between the training programmes and the two professionals' training groups, the majority reported that they received up to 30 hours and between 31 and 60 training hours of the training programme 'Advice about individual student's needs'. Moreover, less than half had received fewer than 30 training hours of the training programme 'Educating children with ASD'. Table

4-16 shows that professionals who received more hours of training were more likely to see 'Advice about students' social and communication skills' as beneficial.

Table 4-16: Percentage (%) of Professionals' perceived benefits from ASD training programmes

Training Programmes	First Training Group 0-30 hours Yes	First Training Group 0-30 hours No	Second Training Group 31-60 hours Yes	Second Training Group 31-60 hours No
Advice about individual student's social and communication needs	65.3	31.9	78.8	21.2
Educating children with ASD	44.3	27.7	40.7	25.3
Adapting policies and procedures	39.7	32.3	36.3	29.7
Auditing the environment to be more autism-friendly	38.9	33.1	35.1	29.9
Working in partnership with families	35	37	32	34
Hearing direct school experiences from those with autism	17.9	51.1	17.1	48.9
Tailored workshops on supporting particular students	7.8	64.2	7.2	58.8

Regarding the ASD programmes, half of professionals had been trained in Applied Behaviour Analysis (ABA) and two thirds reported that they had been involved in TEACCH programmes. Moreover, the vast majority of professionals stated that they felt the ASD training programmes that they chose to complete had sometimes provided them with effective skills. There were no significant differences in professionals' perceptions of the effectiveness of their training, meaning that the first (0-30 hours) and the second (31-60 hours) training groups gave similar responses. However a modest statistical difference was found regarding professionals' perceptions of the effectiveness of their training (d=.24). The first training group with 0-30 hours rated the effectiveness of their training slightly higher than the second group. There were no statistically significant differences in the mean scores across the three experienced professionals' groups with regard to the effectiveness of their training. Although the differences were not significant, the group with the least experience i.e. with less than 10 years' work experience, presented slightly higher scores, suggesting that this professional group felt the training in a ASD session was more effective for them, than for the highest (more than 15 years' work experience) or the middle group (10 to 15 years work experience) (Table 4-17).

Table 4-17: Effectiveness of Professionals' training by years of experience

Training Hours/ Groups of Experienced Professionals	First Training Group 0-30 Hours	Second Training Group 31 – 60 Hours		Lowest (Less than 10 years' work experience)	Middle (10-15 years' work experience)	Highest (More than 15 years' work experience)	
	M(SD)	M(SD)	t	M(SD)	M(SD)	M(SD)	F
Effectiveness of professionals' training in a ASD session	2.08(.55)	1.94(.60)	.33 (d=.24)	2.05(.61)	1.98(.57)	2(.00)	.22

*p<.05 , ** p<.005, *** p<.0
N= 66-72 N = 4 - 40 -103

4.6.2 Professionals' views on parents' access to services

Professionals in this study were very clear about the difficulties that parents faced in accessing services related to their children's needs. Most thought it was very difficult for parents to access early intervention and social support services (66.9% and 62.8% respectively). More than half of the professionals reported that the parents of children with ASD experienced significant difficulties in accessing the services of early intervention, social support and educational provision services. Furthermore, less than half of professionals acknowledged that parents had difficulty obtaining formal diagnoses, therapeutic services and access to medical health centres. On the other hand, more than half the professionals stressed that there were no significant difficulties in accessing music support, speech and language support, occupational support and children's psychiatric services. The results are presented below (Table 4-18):

Table 4-18: Percentage (%) of Professionals' views on parents' access to services

Parents difficulties accessing the following services	Yes	No
Early Intervention Services	66.9	33.1
Social Support Services	62.8	37.2
Educational Provisions	57.4	42.6
Therapeutic Services	45.3	54.7
Medical Health Centres	43.2	56.8
Formal Diagnoses	40.5	59.5
Medical - Education Services	39.9	60.1
Medical Services	39.9	60.1
Home Support Services	35.8	64.2

Psychological Support Services	31.8	68.2
Special Education Support Services	30.4	69.6
Children's Psychiatric Services	25.7	74.3
Speech and Language Support Services	23	77
Occupational Support Services	22.3	77.7
Music Support Services	20.3	79.7

In addition, the professionals in this study, expressed equally strong views when asked about the nature of the emotional difficulties parents experienced when dealing with various aspects of their child's personality. Over half of the professionals reported that parents had difficulty concerning their children's social and communication skills, challenging behaviours and limited self-help skills. On the other hand, only a quarter acknowledged that parents had emotional difficulties and motor skills. The results are presented below (Table 4-19):

Table 4-19: Percentage (%) of Professionals reporting on parents' difficulties

Experiencing difficulties dealing with the following behaviors	**Yes**	**No**
In social and communication skills	75.7	24.3
Behaviours that challenge	68.9	30.4
In self-help skills	64.9	35.1
Language problems	56.8	43.2
Strict compliance to routine behaviour (e.g. ritualistic)	56.8	43.2
Lack of interaction with parents	56.1	43.9
In motor skills	23.0	77.0

The professionals also seemed to suggest that the impact the child's condition has on parents was strong or significant in all aspects of family life. As can be seen in Table 4-20, regarding the perceived effect of the child's ASD condition on parents, more than half of the professionals stated that child's ASD condition affected family interactions, social and recreational interests and social networks. Moreover, a third of the professionals reported that a child's ASD condition had a significant effect on a sibling's life. On the other hand, only a quarter reported that the child's ASD condition had little effect on their social networks.

Table 4-20: Percentage (%) of perceived effect of child's ASD condition on parents according to the professionals

Impact of child's ASD conditions on parents in terms of	Not at all - Little	Enough	Very much- Too much
Family interactions	10.3	18.5	71.2
Social and Recreational interests	17.7	18.4	64.0
Social networks	21.0	24.7	54.1
Occupational and employment opportunities	31.9	18.4	49.7
Education	28.5	23.1	48.3
Siblings	27.2	33.3	39.4

4.7 Professionals' effective partnership with the parents of children with ASD

In terms of how effective their partnership with the parents of children with ASD was, over half of professionals (68.9%) reported that they were satisfied with this cooperation and just over a quarter of them (28.4%) reported great satisfaction. Furthermore, there were no significance differences between the first (0-30 hours) and the second (31-60 hours) of professional training groups in professionals' satisfaction regarding their cooperation with the parents of ASD children. This suggests that the first (0-30 hours) and the second (31-60 hours) professionals' training groups shared similar views concerning their satisfaction with parent cooperation. In addition, there were no statistically significant differences across the three professionals' groups according to years of experience regarding their satisfaction with their cooperation with parents. Regardless of the years of experience, all three groups' members appeared equally satisfied with parental cooperation (Table 4-21).

Table 4-21: Professionals' satisfaction regarding cooperation with the parents of ASD children

Training Hours/ Groups of Experienced Professionals	First Training Group 0-30 Hours	Second Training Group 31 – 60 Hours		Lowest (Less than 10 years' work experience)	Middle (10-15 years' work experience)	Highest (More than 15 years' work experience)	
			t	M(SD)	M(SD)	M(SD)	F

Professionals' satisfaction in terms of their cooperation with parents of ASD children	3.18(.67)	3.18(.74)	.21	3.15(.70)	3.23(.89)	3.50(.57)	.48

*p<.05 , ** p<.005, *** p<.001
N= 66 – 72 N = 4 – 40 -104

4.8 Inter –Professional Collaboration

Nearly three thirds of the professionals who participated in this study (64.9%) seemed to indicate that inter-collegiality had improved opportunities for the development of good relationships. Furthermore, collaboration between professionals was seen as an opportunity to share expertise and to receive encouragement from the senior management team. Despite the positive approach, the percentages in this case were significantly lower namely 58.1% and 54.1% respectively. Specifically, more than half of the professionals acknowledged that inter-collegiality and collaboration had improved through opportunities to develop good relationships and by sharing expertise among staff. On the other hand, the majority of professionals stated that existing policies, organizing out of school activities and encouraging participation in professional development activities did not support inter-collegiality and collaboration among staff.

Furthermore, there was a weak significant difference across the three experienced professionals' groups on whether the existing school policies could support collaboration [F(.22)=6.47, p.002 (d.08)]. However, it appears that the group of professionals with more than 15 years' work experience (the highest) were more likely to perceive existing school policies as useful, compared with the lowest and middle groups. Additionally, there was a small significant difference across the three groups of their perceptions of school collaboration in terms of sharing expertise [F(2,145)=3.05, p .05 (d.004)]. Comparing professionals with the shortest work experiences and those with more than 15 years of experience, more professionals with 10-15 working experience expressed the view that sharing expertise supported collaboration (see Tables 4-22 and 4-23).

Table 4-22: Percentage (%) of Professionals' perceptions of school support collaboration

Support intercollegiality and collaboration among staff through	Yes	No
Opportunities to develop good relationships	64.9	35.1
Sharing expertise	58.1	41.9
Encouragement from the senior management team	54.1	45.9
Approaching collaboration as a long –term school-wide professional development;	29.1	70.9
Encouraging informal INSET	26.4	73.6
Encouraging participation in professional development activities	25	75
Organizing out-of-school activities	19.6	80.4
Existing school policies	18.9	81.1

Table 4-23: Professionals' perceptions of school support collaboration by years of experience

Groups of Experienced Professionals	Lowest (Less than 10 years' work experience)	Middle (10 - 15 years' work experience)	Highest (More than 15 years' work experience)	
	M(SD)	M(SD)	M(SD)	F
Opportunities to support collaboration	.62(.48)	.75(.43)	.50(57)	1.34
Encouragement	.55(.50)	.53(.506)	.50(.57)	.04
School policies	.13(.34)	.28(.45)	.75(.50)	6.47*
Participation in professional development	.27(.44)	.23(.42)	.00(.00)	.82
Organizing out - of - school activities	.20(.403)	.20(.403)	.00(.00)	.49
Encouraging INSET	.28(.45)	.25(.43)	.00(.00)	.79
Approaching collaboration	.33(.47)	.23(.42)	.00(.00)	1.57
Sharing expertise	.54(.50)	.73(.45)	.25(.50)	3.05*

*p<.05, ** p<.005, *** p<.001
N= 4 – 40 – 104

Regarding the perceived benefits of school collaboration, it should be noted that the majority of the professionals (75.7% and 71.6% respectively) perceived collaboration as a process that could influence them at both an individual and professional level. Furthermore, there were no significant differences across the three experienced professional groups regarding the extent to which the different perceived benefits were acknowledged. Although the differences were not significant, those with

less than 10 years of work experience were more likely to perceive professional and organizational level benefits from collaboration than the other two professional groups. Finally, the professionals with more than 15 years' work experience reported slightly higher levels of perceived benefits from school collaboration at the social level compared to the other two groups (lowest and middle groups, Tables 4-24,4-25.

Table 4-24: Percentage (%) of Professionals' perceived benefits from school support collaboration

Benefits from school support of collaboration at different levels	**No**	**Yes**
individual level	24.3	75.7
social level	46.6	53.4
professional level	28.4	71.6
oganizational level	45.3	54.7

Table 4-25: Perceived benefits resulting from school collaboration by years of experience

Groups of Experienced Professionals	**Lowest (Less than 10 years' working experience)**	**Middle (10-15 years' working experience)**	**Highest (More than 15 years' working experience)**	
	M(SD)	**M(SD)**	**M(SD)**	**F**
Benefits at individual level	.75(.435)	.75(.439)	1.00(.00)	.65
Benefits at social level	.52(.502)	.55(.504)	.75(.500)	.43
Benefits at professional level	.74(.44)	.68(.47)	.50(.57)	.76
Benefits at organizational level	.59(.49)	.45(.50)	.50(.57)	1.09

*p<.05, ** p<.005, *** p<.001

N= 4 – 40 – 104

Professionals were asked their opinions about experiencingany negative effects as a result of collaborating with their colleagues. Almost half of the professionals reported feelings of stress, pressure to develop effective channels of communication and the need to compromise with their colleagues could be considered as such. On the other hand, the vast majority of the professionals did not agree they felt a loss of autonomy, or of having their 'territory' being intruded upon and differentiating

between collective and individual contributions during collaborative work came as a result of collaboration. Moreover, there was no significant differences across the three professionals' groups, regarding any negative aspects that they experienced as result of their collaborative work. This suggests that the three professionals working groups shared similar views of their work experiences. Although the differences were not significant, the professionals with between 10 and 15 years of experience (middle group) were more likely to express high levels of stress regarding being under pressure to develop effective channels of communication, having their decisions cross-examined, the time commitment and the constraints they faced compared with the other two groups (lowest and highest group). Furthermore, professionals with more than 15 years of experience felt the need to compromise as a result of collaborative work slightly more than the professionals who had between 0 and 10 years and between10 and 15 years work experience (see Tables 4-26 and 4-27).

Table 4-26: Percentage (%) of Professionals' opinions of experienced losses.

Experienced losses as result of collaboration in terms of:	**Yes**	**No**
Stress and pressure to develop effective channels of communication	48	52
Feeling the need to compromise	42.6	57.4
Having decisions cross-examined	34.5	65.5
Time commitment and constraints	29.1	70.9
Differentiating between collective and individual contribution	16.2	83.8
Feelings of having 'territory' intruded upon	14.9	85.1
Loss of autonomy/independence	9.5	90.5

Table 4-27: Experienced losses associated with collaboration by years of experience

Groups of Experienced Professionals	**Lowest (Less than 10 years' work experience)**	**Middle (10-15 years' work experience)**	**Highest (More than 15 years' work experience)**	
	M(SD)	**M(SD)**	**M(SD)**	**F**
Time commitment and constraints	.25(.43)	.40(.49)	.25(.50)	1.59
Loss of autonomy	.08(.26)	.15(.36)	.00(.00)	1.11
Cross –examined	.33(.47)	.43(.50)	.00(.00)	1.70

decisions				
Need to compromise	.44(.499)	.38(.490)	.50(.57)	.30
Differentiating between collective and individual contribution	.17(.38)	.15(.36)	.00(.00)	.44
Feelings of having 'territory' intruded upon	.14(.35)	.15(.36)	.25(.50)	.16
Stress and pressure to develop effective communication	.46(.501)	.53(.506)	.50(.57)	.23

*p<.05, ** p<.005, *** p<.001 N= 4 – 40 – 104

The professionals' rating of the importance of compatibility in terms of the values and beliefs among the staff, half (50%) reported that compatibility supported staff collaboration to a great extent. Approximately half (49.4%) felt there was enough or a medium level of support. An insignificant number of professionals (0.7%) felt there was little support. Furthermore, there were no significant differences between the first (0-30 hours) and the second (31-60 hours) professional training groups regarding compatibility and support from staff collaboration. Although the differences were not significant, the professionals with between 31 and 60 training hours rated compatibility in values and beliefs higher than those in the group with fewer training hours. Moreover, there was no significant difference across the three groups of professionals (by years of work experience) with regard to compatibility in values and beliefs supporting staff collaboration (Table 4-28).

Table 4-28: Professionals' ratings of compatibility among staff and collaboration by year of experience

Training Hours/ Groups of Experienced Professionals	**First Training Group 0-30 Hours**	**Second Training Group 31 – 60 Hours**		**Lowest (Less than 10 years' work experience)**	**Middle (10-15 years' work experience)**	**Highest (More than 15 years' work experience)**	
			t	**M(SD)**	**M(SD)**	**M(SD)**	**F**
Professionals' compatibility in values and beliefs among staff for support collaboration	3.56(.82)	3.62(.92)	.54 (d=.06)	3.53(.80)	3.68(.94)	3.75(1.50)	.50
N	72	66					

*p<.05 , ** p<.005, *** p<.0

N= 66 – 72 N = 4 – 40 -104

Regarding changes that professionals made to adapt to the school's culture of collaboration, more than half of the professionals stressed that they had adapted in both professional and personal ways. However, over half did not agree that they had made changes in a deeper, philosophical way. There were no significant differences with regard to the perceptions of change across the three professionals' groups (by years of work experience). Although the differences were not significant, the group with more than 15 years work experience (highest group) were more likely to report making changes in order to support collaboration in terms of personal, professional and philosophical ways than did the group with less than 10 years' experience and the middle group (10 - 15 years' work experience) (see Tables 4-29 and 4-30).

Table 4-29: Percentage (%) of Ways of professionals made changes to support collaboration

Changes for adaptation to support collaboration	**Yes**	**No**
professional	64.6	35.4
personal	59.9	40.1
social	55.1	44.9
philosophical	37.4	62.6

Table 4-30: Ways of professionals made changes to support collaboration by years of experience

Groups of Experienced Professionals	**Lowest (Less than 10 years' work experience)**	**Middle (10-15 years' work experience)**	**Highest (More than 15 years' work experience)**	
	M(SD)	**M(SD)**	**M(SD)**	**F**
Personal ways of changing	.63(.59)	.58(.501)	.75(.500)	.24
Social ways of changing	.55(.60)	.65(.48)	.25(.50)	1.05
Professional ways of changing	.68(.46)	.55(.504)	.75(.500)	1.15
Philosophical ways of changing	.37(.48)	.38(.49)	.50(.57)	.13

*p<.05 , ** p<.005, *** p<.001 N= 4 - 40 -104

Professionals acknowledged that they could work effectively alongside parents for the benefit of the child. Working together gives both groups involved a sense of belonging to a team that is willing to put in efforts to achieve the same goal. They can

both contribute as equal partners and their different backgrounds can bring to the foreground different aspects of the condition and as a result, a more complete picture of the condition.

"*It is important to have reciprocal knowledge of both parents and personnel's knowledge, so that you know what you can ask and the parameters you can work with. Also, it is important to know your own role and feel confident, so that you can cooperate well without feeling threatened by your colleague. Certainly, there also should be a sole aim for all of us who are helping the child and we must not compete with each other*" *(Professional 13).*

"*The benefits are the knowledge obtained from the various professions and seeing a condition from all sides. Every professional has a different angle and perspective of a situation that stems from his specialty, so when you marry them all, you have a more collective, more complete picture of the child and the family "(Professional 18).*

"*The major benefits from the cooperation of personnel are that there is motivation, there is a mobilization, a better mood and no one feels that they are alone, especially if some are substitute personnel who are relatively inexperienced, regardless of whether they have learned about autism at University and especially when they are in a particularly difficult school, they understand that they are not alone*" (Professional 32).

4.9 Effective Collaborative practices

The professionals talked about the importance of collaboration for the overall benefit of a child with ASD and indicated the ways in which it could be effective, namely through keeping protocols and working together with schools. At the same time, the professionals suggested continuous interaction between the disciplines, while also asking for clarity of roles and responsibilities in the process.

"*Certainly there could be some protocols, so our signatures are beneath the decisions that will bind us to implement them. We don't even keep proceedings we have paediatric clinics and developmental sections that refer children to us. A second good collaborative practice is good cooperation with KEDDY (Centres of Differential Diagnosis and Support). A third good collaborative practice is good cooperation within*

an access process for children from our structure in preschool education"(Professional 26).

"*There should be continuous interaction among the respective disciplines of mental health (it has been tried and it has great results) and the respective disciplines of education, to become closely communicating vessels and clear up the responsibilities and frameworks that everyone has, could result in be more defined roles in order to have better collaboration"(Professional 28).*

4.9.1 Parent – Professional Interactions

Regarding parents' views about interactions with professionals, over half stated that they had excellent relationships with special needs teachers, speech and language therapists and occupational therapists. Moreover, half reported that they had excellent relationships with their social worker and the children's psychiatrist. Likewise, a third of parents characterized as good their interactions with the educational psychologist. Finally, half of parents stated that they had no contact with a music therapist, yet a small percentage of those who cooperated with this type of therapist characterized their relationships as excellent (see Table 4-31).

Table 4-31: Percentage (%) of Parents' ratings their relationship with the following Professionals

	Poor	Good	Excellent	No contact
Special Needs Teacher	2.7	27.0	66.2	4.1
Speech and Language Therapist	6.5	23.0	62.2	8.1
Occupational Therapist	4.2	25.4	62.0	8.5
Children's Psychiatric	8.2	21.9	52.1	17.8
Social Worker	8.2	21.9	52.0	17.8
Educational Psychologist	4.1	33.8	45.9	16.2
Music Therapist	4.5	13.4	28.3	53.7

In terms of professionals' effective partnership with the parents of children with ASD, it should be noted that over half (68.9%) reported that they were satisfied enough with this cooperation and just over a quarter (28.4%) reported great satisfaction. Furthermore, there were no significance differences between the first and the second training groups in professional satisfaction regarding their cooperation with the parents

of ASD children. This suggests that the first (0-30 hours) and the second (31-60 hours) professional training groups shared similar views concerning their satisfaction with the cooperation. In addition, there were no statistically significant differences across the three professional lengths of experience groups regarding professionals' satisfaction with their cooperation. That is, regardless of the years of experience, the three groups' members appeared equally satisfied with their cooperation (see Table 4-32).

Table 4-32: Professionals' satisfaction with their cooperation with the parents of ASD children by years of experience

Training Hours/ Groups of Experienced Professionals	First Training Group 0-30 Hours	Second Training Group 31 – 60 Hours		Lowest (Less than 10 years' work experience)	Middle (10-15 years' work experience)	Highest (More than 15 years' work experience)	
	M(SD)	M(SD)	t	M(SD)	M(SD)	M(SD)	F
Professionals' satisfaction in terms of their cooperation with parents of ASD children	3.18(.67)	3.18(.74)	.21	3.15(.70)	3.23(.89)	3.50(.57)	.48

*p<.05 , ** p<.005, *** p<.001
N= 66 – 72 N = 4 – 40 -104

Despite the fact that the professionals were satisfied with their co-operation with parents, they were very clear in indicating the factors that posed threats to the quality of cooperation. In an examination of the factors that were perceived as hindering the relationships between professionals and parents of children with ASD, most parents mentioned the lack of resources, whereas parents were divided on the issue of parent – professional communication. Lack of resources was the main obstacle for professionals closely followed by limited communication and limited accountability regarding decision making. A third of parents agreed that the limited accountability of professionals regarding decision making and their time pressures were hindering factors. Specifically, 37% indicated the time pressure they feel as practitioners was an important aspect of possible problems in the cooperation between parents and professionals.One in three parents reported lack of ASD specific knowledge was an obstructing factor in their relationships with professionals. Likewise, a third of parents felt that professionals were not adequately skilled and educated about ASD. One in five

parents stated that their own limited time and one in four their lack of confidence in dealing with professionals as an obstacle. However, almost a quarter saw lack of knowledge and understanding about ASD, as hindering factors. The results are presented below (Table 4-33):

Table 4-33: Percentage (%) of factors that hindered working relationships between professionals and parents of children with ASD

Factors that obstructed parents – professional working relationship	Yes	No	Don't Know
Policy and practical constraints due to lack of resources	56.9	27.8	15.3
Limited communication	45.2	46.6	8.2
Limited accountability regarding decision making	37.5	47.2	15.3
Professionals' time pressures	37.0	35.6	27.4
Lack of knowledge and expertise on ASD on experts' part	30.1	54.8	15.1
Parents' own limited time	26.4	69.4	4.2
Parent and/or experts' lack of shared beliefs and values	25.4	57.7	16.9
Parents' lack of confidence in dealing with professionals	23.9	60.6	15.5
Parents' lack of knowledge and understanding of ASD	19.4	75.0	5.6

Most parents reported that the eight series of statements (see Table 4-34) were very important for them. Over half of parents reported that their involvement in their child's therapy and the exchange of information with educational professionals, were priorities for them. Despite being a priority, participants felt that their needs were either partly met or unmet on both accounts, with percentages of 75% and 56.8% respectively. It can be argued that there is a pattern in the parents' responses. All the statements included in this question, touched issues that are very significant for parents. As a result, the percentages either come close to or exceed 90%. At the same time, the majority of the sample members clearly suggested that their needs were only partly met by the professionals. The results are presented below:

Table 4-34: Percentage (%) of Importance of parents' working relationships with professionals and the importance to which of these working relationships were satisfactory

Parents' working relationships with professionals	Not – Slightly Important	Important	Very Important	Unmet	Partly Met	Met
Parents involved in child's treatments and therapies		37.0	63.0	16.2	58.8	25.0

Parents exchange information with educational professionals	2.7	38.4	58.9	12.2	44.6	35.1
Professionals offer opportunities for parent training in remedial programmes (e.g. ABA, TEACCH)	8.4	37.5	54.2	31.9	47.8	20.3
Parents cooperate with child's special teacher	1.4	45.2	53.4	8.8	57.4	33.8
Parents consider suggestions and feedback from professionals	2.7	45.2	52.1	7.5	64.2	28.4
Professionals provide a welcoming atmosphere	8.2	42.5	49.3	1.5	53.7	44.8
Parents involved in the individual education plans	12.4	38.4	49.3	25.0	57.4	17.6
Value parents' opinions in decisions regarding treatment and education interventions	8.3	47.2	44.4	8.8	60.3	30.9

As can be seen in Table 4-35, there were no significant gender differences reported regarding the working relationship between parents and the professionals, indicating that both mothers and fathers rated similarly the importance of having a good working relationship with professionals. Although differences were not statistically significant, fathers rated their working relationships with professionals slightly higher than mothers with respect to: the provision of a welcoming atmosphere, involvement in the education plans and having their opinions and decisions valued for their child's treatment and education interventions. By contrast, mothers evaluated their working relationships with professionals more highly than fathers in terms of the following: suggestions and feedback from the professionals, exchange of information, their involvement in their child's treatments and therapies, their cooperation with the special teacher and the opportunities for parent training in remedial programmes. Furthermore, there were no statistically significant differences regarding parental education levels with regard to parent-professional relationships.

Table 4-35: Parents' working relationships with Professionals by gender and education

	M(SD)	M(SD)	t	M(SD)	M(SD)	t
	Mother	**Father**		**Compulsory Education**	**Higher Education**	
Provision of a welcoming atmosphere	1.41(.49)	1.43(.50)	.05	1.44(.50)	1.40(.49)	.35
Suggestions and feedback from professionals	1.35(.48)	1.14(.35)	17.93	1.25(.44)	1.31(.47)	1.34
Information exchange with educational professionals	1.30(.46)	1.14(.35)	10.65	1.31(.47)	1.20(.40)	4.38
Involvement in child's treatments and therapies	1.23(.42)	1.10(.30)	9.30	1.21(.41)	1.17(.38)	.71
Involvement in individual education plans	1.13(.33)	1.19(.40)	1.69	1.18(.39)	1.11(.32)	2.47
Cooperation with child's special teacher	1.43(.50)	1.33(.48)	2.44	1.39(.49)	1.40(.49)	.01
Valuing decisions regarding treatment and education interventions	1.34(.47)	1.43(.50)	1.34	1.42(.50)	1.31(.47)	3.02
Offering opportunities for parent training in remedial programmes	1.26(.44)	1.24(.43)	.09	1.18(.39)	1.31(.47)	6.59

*p<.05 **p<.01 *** p<.001
N= 21 – 47 N= 32 - 35

4.9.2 Parental Involvement/ Training Programmes

Parents and professionals acknowledged the need to work together in order to maximize the effectiveness of the child's ASD related programme. At the same time, the professionals raised concerns regarding the sensitivity of the situation. It seems that there is a fine balance between the two partners that is very easy to lose as the extracts below suggest.

"Being involved in my child's individual programme, reduced my stress a lot" (Parent O).

"The ASD education of parents helps the parents to get involved a lot. In the field of special education, fortunately, most are professionals so they should have a positive attitude to parental involvement" (Parent E).

"The first advice I received, for example, was not to get too friendly with the parents of children, because it will not be an equal friendship. Parents will become more demanding and ask for things that you will not be able to give" (Professional 28)

4.9.3 Factors that affect parental involvement in the diagnostic and educational services

Although parents as well as professionals acknowledged and agreed on the importance of working together for the benefit of the child, they seemed to be equally clear about the difficulties of the process. In this regard, they talked about ignorance on both sides and the difficulty that parents face in order to open up to professionals about their child's needs. Finally, time constraints were considered to have an adverse effect on the process, as the following extracts indicate.

"What creates difficulties for parental involvement is ignorance on both sides, when the professional doesn't know what a child with special needs means, how to deal with or how teach a child with special needs and neither does the parent know about ASD. All this ignorance creates problems. When there is knowledge, any problem can be solved. When you're ignorant, you do not understand what the other person is saying, don't realize nor sing from the same hymn book" (Parent H).

"The main factor that affects parental involvement is the parents themselves. Often, in order to express their concerns, they expect to be asked about what kind of help they want. On the other hand, if they can be given confidence, they will get help if needed" (Professional 15).

"Time impedes cooperation with parents because it's not recognized and it's not considered as a necessary element for professionals. In my opinion, it takes a lot of time to achieve your goal. First of all, parents must be trained because the children spend most of their time in the home" (Professional 30).

Next, the participants were asked to assess their experiences with these professionals in terms of the child's diagnostic procedure. Most parents agreed that their child's diagnosis was completed in a timely and professional way, with the professionals being respectful and discreet, answering their questions honestly; however, a large number expressed doubts about the ability of the professionals to offer help regularly, not just at times of crisis. Furthermore, half of the parents stated that the professionals helped them to deal with their fears regarding their child's future, and nearly half reported they received clear information on the ASD profile, their financial entitlements and appropriate educational provision for their children. Over half of the parents disagreed that they received clear information on educational resources to inform themselves about ASD, while a quarter were neutral about this (see Table 4-36).

Table 4-36: Percentage (%) of Parents' rating of their experiences regarding their child's diagnosis

Experiences regarding child's diagnosis	Disagree/ Strongly Disagree	Neutral	Agree/ Strongly Agree
Child's diagnosis was completed in a timely and professional manner.	21.6	16.2	62.2
• Parent received clear information on: ASD profile and needs (e.g. dealing with behavior challenges)	37.8	16.2	45.9
• Financial entitlements available to child and family;	31.5	24.7	43.8
• Suitable educational provision in a special or mainstream school	37.8	18.9	43.2
• Educational resources to educate parents about ASD	57.5	20.5	21.9
The professionals: • Answered questions honestly	13.7	19.2	67.1
• Showed respect and were discrete	11.0	26.0	63.0
• Helped parents deal with fears about child's future	25.7	24.3	50.0
• Offered continuous services rather than only at times of crisis	27.4	30.1	42.5

There were no gender differences evident regarding parent-professional interactions. This suggests that mothers and fathers reported similar views on their experiences regarding their children's diagnosis. However, a moderate gender difference was found regarding the information parents received about the ASD profile and needs [t (52) =3.15, p.02, (d.61)]. Fathers expressed a higher degree of agreement

about receiving information concerning the ASD profile and needs than mothers. Furthermore, fathers assessed their experiences with the professionals slightly higher during their child's diagnosis in terms of helping them deal with fears for their child's future, showing respect and being discrete, answering their questions honestly and offering their services on a continuous basis. Moreover, there were no differences in the ratings of parents-professional interactions across parental educational levels. However, a moderate statistical difference was found regarding the information provided about appropriate educational provision in a special or mainstream school [t (52) =0.84, p.02, (d.55)]. That is, those parents with only a compulsory education background rated more highly the importance of this information than those with a higher education qualification (Table 4-37).

Table 4-37: Parents - Professional Interactions / Experiences by gender-education

	M(SD)	M(SD)	T	M(SD)	M(SD)	T
	Mother	**Father**		**Compulsory Education**	**Higher Education**	
Experiences of child's diagnosis	2.40(.82)	2.41(.85)	.040	2.49(.76)	2.32(.88)	2.77
ASD profile and needs	1.92(.92)	2.45(.80)	3.15* (d=61)	2.14(.14)	2.03(.15)	1.57
Suitable educational provision	2.06(.91)	2.05(.89)	.301	2.30(.84)	1.81(.90)	.84* (d=55)
N	52	22		37	37	
Financial entitlements	2.02(.88)	2.36(.79)	.53	2.14(.88)	2.11(.85)	.35
Educational resources	1.61(.82)	1.73(.82)	.016	1.76(.86)	1.53(.77)	1.51
N	51	22		37	36	
Help of Professionals regarding the future of child	2.21(.84)	2.32(.83)	.024	2.27(.80)	2.22(.88)	1.34
N	52	22		37	37	
They showed respect and were discrete	2.51(.73)	2.55(.59)	1.40	2.57(.64)	2.47(.73)	1.23
They answered all our questions	2.49(.75)	2.64(.65)	1.96	2.46(.80)	2.61(.64)	3.71
They offered services continuously rather than	2.12(.84)	2.23(.81)	.056	2.16(.83)	2.14(.83)	.00

only in times of crisis						
N	51	22		37	36	

*p<.05 **p<.01 *** p<.001
N= 22 - 52 N= 36 – 37

4.9.4 Professionals' Challenges

The professionals in this study acknowledged that in their attempt to fulfill their professional duties, they had to face challenges directly linked to the nature of the children's condition, especially communication. The professionals also found it hard to establish a bond of trust with the children as well as manage their challenging behaviour. Finally, practitioners found the work and the effort both sides have to commit in improving children with ASD's social capabilities challenging.

"The challenges with a child who is on the autism spectrum is to win his or her confidence, establish collaboration and personal contact in order to discover together his or her interests and build his education after identifying his deficits. I think this is very difficult in our job. It is quite difficult to communicate and collaborate with children who are on the autism spectrum" (Professional 8).

"I believe that the management of challenging behaviour, or the ability to find ways to manage this behaviour and understand these children is much more complicated than it initially seems to be" (Professional 17).

"My challenge is their social part. Many children with high-functioning autism aren't able to learn in a standard way, but they learn. The point is to use their knowledge in their social life. The biggest challenge is how to help the children manage to join a social group. It's really important to learn to interact with their peers and with those around them. This is the most challenging issue. It's also very important to pass from standard behaviour to social behaviour" (Professional 21).

At the same time, the professionals acknowledged challenges that have nothing to do with the child's condition. Instead they referred to their personal frustration due to imponderable factors. Furthermore, they mentioned difficulties that appear to be due to

parents' lack of knowledge about autism as well as those that come as a result of the cooperation of parents and teachers of children with ASD.

"The biggest challenge that I have faced as a professional is frustration. You think that you have organized everything; you have recorded and you have also prepared the best program with the best material and a dog passes near the child. The child has a dog phobia and everything is destroyed. Imponderable factors and especially ones with sensory content, play an important role in our profession" (Professional 19).

"The biggest challenge is when you have groups of parents and teachers together. They are the most difficult but the most useful groups, too. You have to be the mentor in order to understand each other's problems. And this is a challenge" (Professional 23).

"The biggest challenge is the inadequate education of parents whose children have been diagnosed by doctors. They give them a diagnosis without informing them adequately. There are no social services to help these parents. As a result, they don't know what the next step is. There are doctors who don't mention the term 'autism' and throw the ball to the therapists who are not allowed to make diagnoses. This is very stressful for them. This is a challenge" (Professional 34).

4.9.5 Difficulties accessing professional expertise

The professionals themselves acknowledged that it was difficult to find qualified professionals to offer the services a child with ASD requires. According to their rationale, this is due to the state's inability to present an organized front as far as finding appropriate professionals is concerned. Adding to this, the participants indicated that further training is necessary for doctors to be able to identify sooner the indicating signs of ASD as well as the professionals with the appropriate education background.

"Who are the certified and qualified professionals? Over the last few years we have talked about licenses, about guidance and control of this situation. It would be fair to begin from the birth of a child and have a systematic check on him or her. The Ministry of Health must have the first word. The system must be better organized so the children who have difficulty in their development can be monitored from the beginning. Through

their developmental years, this institution must be able to help these children and their families and give them some everyday lives. I am afraid that the public domain in Greece will never be able to have such a role, because we can't organize it, this is the truth" (Professional 12).

"Another challenge is that pediatricians are not sufficiently educated to realize the first signs of autism at an early age, and we waste a lot of valuable time" (Professional 26).

"Most of us have attended some seminars. This does not mean that we have acquired specialized knowledge. You can't be responsible for a child on the autistic spectrum just through seminars. This idea is a crime. Everyone can achieve anything, we all know everything. You have to have undergone training, serious post-experience training not just seminars. Some teachers have only attended seminars and some others do far more damage than good. You have to really want to work in special education" (Professional 31).

4.9.6 Professionals' Changes

The professionals in this study seemed to suggest that, despite the challenges and the difficulties involved, working with children with ASD had positively influenced their character. This is illustrated clearly in the following quotes.

"The most important area that I have gained in is the patience and the fact that I have become a much better listener" (Professional 10).

"I have become more human and more lenient" (Professional 24).

"It has probably changed my personality, since I have acquired greater patience and I have greater flexibility. It has enhanced my vision of what to expect from them in terms of behaviour. I am impressed by the achievements of some children with high functioning autism" (Professional 33).

4.10 Difficulties that hinder parent –professional co-operation

a. <u>Difficulties in communication due to parents' unwillingness to accept professional knowledge and expertise</u>

Parents tend to reflect their own needs for consulting and emotional support upon professionals and this makes it difficult for the professional to remain objective. In addition, parents feel the need to control every step of the process, even if the sources of information that they use to form their opinion might not be the most appropriate. The following quotes reflect the ideas suggested above:

Professional 29 reported: "*The parents' education and their social status are important factors. I think that genetic and environmental reasons cause this situation. I believe that these parents do not always accept the outcome of consultations. However, I don't know if consulting can always solve their issues. They come to the psychologist and they want to overcome everything. They don't go to the psychologist in order to talk to the doctor who monitors their child. They show me their anger, their denial, their ambivalence, their depression and expect me to support them. I try to help them but neither I am an expert nor it is my job, nor have I the time to spend on it. I have to take care of the child and sometimes in this period of time, our collaboration stops. Many times our collaboration stops for senseless reasons. Uneducated people don't analyze things very much".*

Professional 32 stated: *"Parents have never been welcome in Greek schools. Parents have developed the last few years - through daytime low-level TV programmes - the idea that they must take control in the worst way, for example, having an opinion on issues without having the appropriate knowledge and, on the other hand, not participating in issues where their participation is crucial. And this is a big misunderstanding. The parent's role is important, but having an opinion on everything is ridiculous".*

b. <u>Parents' ability to accept their child's condition</u>

The results indicated that the parents of children with ASD find it difficult to come to terms with their child's condition. They were reported to refuse to accept the problem and this results in them feeling frustrated and disbelieving. By contrast, if parents are able to accept the reality of having an autistic child then their hopes and expectations will adjust to the new circumstances and help the co-operation flourish. An important element of this equation is the ability of the professional to consult parents.

Professional 4 stated: *"Professionals sometimes don't have the ability to consult parents. This problem has to do with the professional's lack of knowledge about consulting. On the other hand, a big problem is the parent's refusal and their need to have a normal child. Parents focus on issues that are not so important and sometimes are even pointless. Professionals are more interested in the child's social absorption at school than in the learning part. Furthermore, another problem is parents' disbelief".*

Professional 18 reported: *"Despite the fact a good relationship of children with ASD has been developed, the difficulty in communication with parents still remains. Time is necessary. Certainly, they have their own issues that relate to the recognition of their child's condition. Parents who have accepted their child's condition, to a greater or a less extent, express their thoughts and they ask for the expert's advice more easily. If they haven't accepted this condition, they don't express themselves, they may conceal things and they may feel that the expert wants to control them".*

Professional 36 stated: "*Parents can have high expectations of their child. When their expectations are realistic and they know what to expect from the experts and what they want from their child, they cooperate better with all sectors".*

c. Time

The professionals indicated that if parents followed their suggestions, the results would be positive for the children, but parents need to be open-minded. Professionals in this study accepted that parents tend to feel frustrated with the situation, but that parents need time to accept their child's condition. They also need time to establish a good relationship with professionals, something that becomes even more difficult due to their work commitments.

"*It depends how open-minded they are about following the possible instructions from school. In cases where parents follow these instructions, the results can be spectacular. An important obstacle is the lack of time. Parents work a lot and can't get a day off to go more often to the school" (Professional 16).*

"When I sometimes try to tell and explain something, they are unwilling. But this has to do with the time. Parents need time to accept the truth. So time is an obstacle to this cooperation. Maybe the parent has accepted some things but there has not been any thorough communication" (Professional 22).

"It depends on the parents. As the children grow up, the relationship between the family and children becomes more complicated and so then is the cooperation between school and family. They are tired, have visited experts, and still see that the problem remains unresolved, especially during adolescence, it's like they are undergoing huge changes and feel disappointed. When the children are small and parents are in the process of searching to find specialists, they are more open" (Professional 38).

d. Personal chemistry

The professionals in this study indicated that every case that they deal with is unique as is every parent. As a result, the extent to which parents and professionals can develop meaningful collaboration and interaction depends on the personality of the individual. Despite this, listening to what parents have to say, finding common ground to work on and gaining parents' confidence could be ways of working toward achieving meaningful interactions.

"Each collaboration is difficult because it has to do with the defenses and the data of each parent. But for parents with children with ASD in particular, it is a good challenge, if you like, positive contact with those who will deal with their child because in this way their defenses are decreased and this helps them hear and see how they could really help their children. Parents are positive, generous and receptive" (Professional 13).

"The positive mood of somebody means they want to cooperate, because there are people who want to work individually. It has to do with their knowledge and experience of autism, knowledge in the sense of using a common glossary, terms of reference, that is, to say something and be able to communicate with others, how everyone will see the same thing, but from their point of view"(Professional 27).

"*The first and foremost factor is that we need to gain the confidence of the parent, since due to the severity of the disorder, parents have multiple daily messages from several therapists. This prevents any collaboration with them in a multi-dimensional way, which creates a serious issue in communication. You must try hard to gain their confidence while having in mind a certain direction which is multidimensional and it doesn't address a single therapeutic approach*" *(Professional 35).*

4.11 The Continuity and Stability of Services

The participants in this study suggested that it was difficult for parents to establish a sense of continuity between home and school for their children. Another practical issue that hindered communication was bureaucracy. It is time consuming and made it hard for parents to create the circumstances for meaningful communication with social service agents. Finally, the participants highlighted another issue that needs to be taken into consideration when lack of communication between parents and professionals is discussed, that is, the services that could offer help are understaffed.

"Parents are not always able to implement the directives in the house and they want home based services. This is sometimes accepted and sometimes not. Practically, the biggest problem is the transfer of the directives at school. Another problem is the dynamic of the family. For example, if you have a dad who wants to follow the program and mum is reluctant, that means that there is a negative dynamic between the couple at home"(Professional 6).

"*Due to workloads, parents don't communicate frequently with us. They should communicate more often with us. This is not always feasible because there are a large number of the people who receive support in relation to the number of the service personnel. By the time the service is adequately staffed, valuable time has passed. When schools open, the services of the Ministry of education are not adequately staffed and there are tensions" (Professional 25).*

"*I think that the bureaucracy is a big challenge for ensuring continuity in service support. You want to refer a child to the specialist and there is a whole process to follow. Finally, the child is able to go there after three months, because the assessment*

of the educator has noted she is within the autistic spectrum disorder. Very often the assessment by public bodies is not purposeful, without wishing to underestimate their job because good work is done (e.g. A.P.H.C.A.) Association for the Psychosocial Health of Children and Adolescents. If parents arrange an appointment and miss it, it will be held two months later. This is a practical problem" *(Professional 40).*

Their comments bring to the foreground the need for permanent staff, which in turn, will help parents establish relationships of trust and confidence with the same professional over time. The participants also suggested that there is a need for a common approach and cooperation between specialist teachers and parents. They need to understand and trust each other instead of feeling competitive.

"*Schools must be manned by permanent staff. When the psychologist and the social worker changes every year, how will the parent create a relationship of confidence and talk to them? We are talking about personal issues, not educational programmes. We are talking about the parents' feelings and the stress they have at home. This is a vicious circle" (Professional 2).*

"The professionals must learn to understand the needs of the parents and give them the appropriate consideration. And parents are often try to manipulate the professionals, because they expect to get what they want to hear rather than the truth. Having as many meetings as possible and the appropriate professionals can provide safety nets to parents. Parents are anxious about the future of their children. When you show them the direction towards a safer future for their children, they feel more confident"
(Professional 16) .

"The teachers definitely need to make an effort to bring the parents into schools, to persuade them that their purpose is to do the best that they can for their children. I think they must earn that trust because many see us as rivals" (Professional 27).

4.12 Key findings of the parents'- professionals' interaction

The professionals interviewed in this study were aware of the challenges that parents of children with ASD face. These challenges ranged from accessing educational

and social support to the emotional implications of raising a child with significant communicative and social needs. They saw inter-professional collaboration as important but also experienced stress in their attempts to work with others. When it comes to working with parents, some professionals faced obstacles in ensuring that parents understood them and accepted their professional advice and expertise. Finally, they felt that collaboration was an effective way of meeting ASD children's needs. The findings indicated that, regardless of their years of experiences, the three professionals' groups (lowest, middle and highest) appeared equally satisfied regarding their cooperation with the parents of children with ASD. Professionals with lower and middle work experiences reported that sharing expertise supported collaboration in comparison with the highest professionals' group. Furthermore, the highest professionals' group (more than 15 years work experience) noted slightly higher levels of perceived social benefits from school collaboration and made more personal, professional and philosophical changes compared to the other two professionals' groups (lowest and middle) to support collaboration.

In addition, fathers rated their working relationships with professionals slightly higher than mothers with respect to having their opinions and decisions valued concerning their child's treatment and education interventions. By contrast, mothers rated their working relationships with professionals higher than fathers in terms of suggestions and feedback from the professionals. Parents with higher education evaluated their working relationships with professionals regarding offering opportunities for parent training in remedial programmes as better than parents with compulsory basic education. Moreover, these parents reported their interactions with professionals regarding providing suitable educational provision in a special or mainstream school were better compared to those with higher education.

4.12.1 Key findings of Professionals' perceptions of school support collaboration by years of experience

Professionals' perceptions of school support collaboration	Lowest (Less than 10 years' work experience)	Middle (10 - 15 years' work experience)	Highest (More than 15 years' work experience)	F
School policies	.13(.34)	.28(.45)	.75(.50)	6.47* [F(.22)=6.47, p.002 (d.08)]

Sharing expertise	.54(.50)	.73(.45)	.25(.50)	3.05* F(2,145)=3.05 p .05] (d.004)

4.12.2 Key findings of Parent – Professional Interaction/Experience by gender and education

Parent – Professional Interaction /Experience	**Mother**	**Father**	**T**	**Compulsory Education**	**Higher Education**	**T**
ASD profile and needs	1.92(.92)	2.45(.80)	3.15* [t(52)= 3.15, p.02, d.61]	2.14(.14)	2.03(.15)	1.57
Suitable educational provision	2.06(.91)	2.05(.89)	.301	2.30(.84)	1.81(.90)	.84* [t(52)= 0.84, p.02, d.55]

4.13 The role of the state

Both parents and professionals gave their views on the role of the state in supporting families with children with ASD. Their views on ASD policy and ways in which the state could support the lives and schooling experience of children with ASD were discussed. The thematic units presented in this section are as follows: a) Recognition of children with ASD b) Systematic Victimisation of parents and children with ASD, c) SEN Policy, Structural Constraints/Austerity d) Access to services (public and private) /Benefits incurred e) School experience and f) Financial Challenges / Welfare State.

4.13.1 Greek State's recognition and support for children with ASD

The participants suggested that although ASD is recognized as a disability by the state and some help is offered in the form of benefits, treatment and therapies, there are gaps in social policy. They also recognized that the problem has intensified since 2008 due to the economic crisis. The country's weak economy makes cooperation between Ministries and public agencies harder. Moreover, the participants in this study claimed that, for the state, inclusion is a 'value laden' term that is interpreted differently in

different contexts. They seemed to hold similar views about the term *pervasive developmental disorder*, which is considered an umbrella term, the interpretation of which makes the creation of a complete profile of the strengths and the weaknesses of the child challenging. Finally, the participants seemed to think the services offered from the state regarding the diagnosis of the condition were adequate despite the limited services on offer from the state to ASD children. This applies to all aspects of the condition with the exception of the diagnostic process. They suggested that there are still difficulties that need to be overcome.

"All children with disabilities and children with autism are recognized by the Greek state. The state provides several amenities to these children but there are not many public services for them. There are some benefits, such as the allowance of special education and the treatments which are covered by the state. Probably the state could offer a larger number of therapies and schools could be sufficiently well manned. Within this context the benefits could be slightly better, but for the Greek State, this would be luxury" (Professional 9).

"The identification of children with autism doesn't always happen because we don't have the proper services. Unfortunately and fortunately everything in Greece has to do with the people you can cooperate with. You can refer to inclusion generally and vaguely. You have to know in what context you speak" (Professional 22).

"I think that in comparison with other special educational needs, the handling of the autistic diagnosis is satisfactory. In other areas such as social policy there are deficits. However, diagnostic part is adequate, although the term pervasive developmental disorders*, is broad and it does not help us discover the difficulties and the abilities of these children" (Professional 37).*

The interviewees also suggested that the state offered a limited amount of funding, which in turn influenced the quality of public services offered to children with ASD. Those parents who could afford it were forced to turn to the private sector, while those who were not financially capable of funding the therapies or treatments of their children had to rely on the public sector services. These circumstances could result in the child's progress being delayed or suspended.

"Special education has been a victim in this country for years before the crisis. Generally, no one from the government has ever invested in the special education of Greeks" (Parent K).

"I believe that the state doesn't offer everything that the teachers and the families of children with ASD need. It gives a small amount of funding each month which is insufficient to meet those needs and also the state sends people who aren't qualified to give parallel support to children with ASD. I have seen some ASD kids whose parents pay privately their parallel support is going well. When the parallel support comes from the state, because the parents cannot pay continually out of their own pocket, we can see that the children regress. I couldn't believe that it would happen but I lived it as experience and it wasn't pleasant at all" (Parent H).

4.13.1.1 Structural constraints

Although interviewees acknowledged that the state recognizes the problems and there has been some work towards addressing them, a lot more is needed. Participants raised the issue of early intervention as well as that of shortage of personnel and lack of training for children with autism after the end of formal schooling. Professionals suggested that there is lack of infrastructure to help children with ASD after their parents and guardians have passed on. This will be achieved through education and information**.** Participants in this study suggested that there is a lack of public centres related to ASD. They also claimed a shortage of qualified professionals. Moreover they said that doctors in public services try to do the best they can in order for parents to claim more money in benefits. Public services offer advice and guidance regarding key everyday issues that ASD condition raises. At the same time, participants indicated that doctors might cooperate with private centers and treat parents as potential clients privately. These ideas suggested below:

"There have been several steps, but extra steps are necessary especially in cases with severe autism in which the children face serious problems and they cannot be functional. We need more supportive structures apart from the special school. Our society is not entirely open to autism and generally in special training. Our society and of course our schools need more information about autism" (Professional 11).

"Unfortunately there are too many problems. Starting from the early intervention in which there are no structures nor have they been foreseen to be created. And then the education system with the minimum of resources and the difficulties in recruiting teachers has many problems and of course on the part of adults where things are hopelessly after school. There are no structures for adults to continue their education afterwards or workshops in which they can be occupied. Also, there are no structures to ensure their safety after their parents have left this life" (Professional 25).

"With the austerity we don't have the potential for treatments. There is no possibility for qualified personnel, even for personnel generally, which can deal with children with disabilities. There is no money even for the environmental interactions from a psychiatrist or by doctors. There is a difficulty in personnel training who deal with these children" (Professional 36).

Parents and professionals were clear that in theory and in accordance to law requirements parents of children with ASD can and should claim financial help from the government. At the same time, they claimed that policies are not implemented and thus parents face difficulties in accessing both services that relate to the improvement of their child and a small amount of money in the form of social benefit. In addition to the lack of money professionals also suggested parents' level of education is important for accessing services. Parents' level of education influences the nature of the services they seek and the way parents and children work together. The following extracts reflect the ideas suggested above:

"Generally, the families of our students, considering the existing social policy and the welfare protection, are on a high level, both in theory and in law, however in practice when these policies are not applied then families face a lot of difficulties in accessing these services" (*Professional 17).*

"Of course it is a matter of financial capacity. Parents who don't have economic problems do not have difficulty in accessing services. On the other hand, parents who can't afford it have a great difficulty. Perhaps the level of their education is really

important in this occasion too. They don't know where exactly to go and we don't have the ability to accompany them which would be very good too" (Professional 36).

Participants also were very clear that there are many problems that the state needs to deal with for the quality of special education provided to children with ASD to improve. To this end, participants suggested parallel support for all children in public schools as well as specialized care to each child depending on the severity and intensity of the symptoms. Interviewees moreover claimed that the problems they recognized can be observed in private schools as well. They claimed lack of infrastructure once again. In this regard, they mentioned that more need to be done for the severe cases in the private sector while they also mentioned the need for after school services for parents. The following extracts illustrate the ideas suggested above:

"I believe that people are more sensitive from the past and there is a progress. I believe that younger teachers are more informed. I think that there is a big difficulty, which I do not believe that starts from teachers but from the present economic situation of the State, in providing parallel support in parallel to all the children. I think that a lot of children need parallel support and not only children with high functional autism. Teachers are not against it because those who know, they are also sure that parallel support helps the whole class work right and not only the child itself. I think that the other difficulty is the special schools, which unfortunately are a few so we are not able to sort them out and we cannot have a specialization. That would help the children with autism a lot because either they are forced to be educated with children who are not autistic and they have other skills and other needs or due to the shortage of gradation (depending on the functionality of the child) there are unfortunately many issues that create difficulties to the child and his family and to the teacher too" (Professional 7).

Parents and professionals suggested that austerity has influenced every aspect of society. As a result, the state offered less consideration to the needs of vulnerable social groups. The findings in this study indicated changes in practical issues that benefit children. Participants mentioned lack of therapeutic models for children in the public domain as well as cut of the disability allowance. Austerity also influenced schools in the form of lack of personnel and school merges. These views were highlighted below:

"The austerity brought changes in practices. The sessions were reduced from twenty-four to eight for ASD children. Also, they considered the disability and the needs of these people even less. Almost all disability allowances were cut and there is great corruption at this point. Austerity has increased corruption the most" (Parent I).

"The economic crisis has affected everyone and, of course vulnerable social groups. Recruitment has also been cut back, and the number of students in school and classrooms has grown because of school mergers. This situation does not help children with disabilities" (Professional 3).

"In the age of austerity, disability is afflicted. When there are no jobs for "able-bodied", there won't be any for handicaps. In Greece, everything is provided privately. There are no therapeutic models in the public domain. Everyone knows that access to private therapeutic centers is even more difficult" (Professional 32).

Furthermore, parents' perceived views on the impact of austerity on SEN services were examined. Over half of parents reported a substantial effect caused by austerity measures on the provision of services for their children with ASD with only a quarter expressing the view that there was minimal effect. Moreover, there were no gender and education differences found regarding the association of austerity measures and services provision suggesting that both mothers and fathers across educational levels shared similar views concerning the impact of austerity on ASD services.

Interviewees further suggested that due to austerity municipalities cannot afford offering financial assistance in the form of afternoon activities for children with ASD. On the other hand parents find it very hard to pay for them on their own. At the same time, some municipalities can offer services like KDAP or they can find money through European programmes. The number of children that apply to participate are far more than the numbers municipalities can accommodate. The findings are presented below:

"We don't have any support from our municipality and during any economic crisis, it is really difficult for us to afford it. We fight through our Parents' Association to inform municipalities and make them understand our children's problems and need" (Parent P).

"There are a few municipalities that have created such programs using money from European funding. The problem is that autistic children cannot take part even in sports activities which are more often available" (Professional 14).

"Furthermore, the local authorities should have afternoon supportive services, such as the KDAP (Centres of creative activities), which operate in some municipalities. These services are not enough yet, nor meet the real needs of children. At the same time, parents have constantly applied to the local authorities for the establishment of afternoon structures for their children's creative activities" (Professional 28).

Interviewees also argued that due to fragile economy it is very difficult for parents to claim what the state should rightfully offer to their children. Parents claimed that they faced bureaucracy in their attempt to communicate with the appropriate professionals while professionals themselves indicated the need for the services to be organized better and communicate more effectively if they are to become efficient in the provision of services for the vulnerable members of the population. Representative extracts are presented below:

"Nowadays, services that are provided are sparing due to the economic misery. We believe that we should facilitate parents, because many times in order to get this help they have to spend a lot of time in the services, they must communicate with a lot of people and sometimes they have to strongly assert their rights. Better organization and a larger availability of funds are needed for these children" (Professional 39).

"We had mostly bureaucratic difficulties. Municipalities don't communicate with Ministries. There is no consultation and cooperation between the Ministry of Education and the Ministry of Health for obvious things (medication in cases of severe mental illnesses in children)" (Parent C).

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services provision suggesting that both mothers and fathers and parents across educational levels shared similar views concerning the impact of austerity on ASD services.

Participants in this study indicated that parents have to deal with added costs due to the condition of their child. This makes the situation that parents have to face even more difficult due to the austerity times in Greece is currently going through. Support from the state is very limited and public services do not offer parallel support in an attempt to cut costs. Given the circumstances the cooperation between parents and professionals is very difficult. Participants seemed to suggest that the cooperation between professionals in the private and public sector is equally difficult. The following quotes reflect the ideas suggested above:

"We had private behavioral therapy crashed the first two years, to prepare our child to go at mainstream primary school. These costs added up. Social welfare was absent" (Parent N).

"The parents have been affected because they have financial problems and greater intolerance for issues that occur at school. They have neither the financial nor the psychological ability to stand next to their child and also beside us" (Professional 20).

"During the period of austerity, most professionals in the public centers feel like partisan soldiers who won't hesitate to throw our kids in the Keadas just to cut costs. KEDDY's scientist team must give their opinion of our child and parallel support rather than engage in economic policy. On the other hand, the crisis has not facilitated nor made cooperation with private centers easier" (Parent O).

Participants in this study seemed to suggest that the lack of financial support from the state has intensified the financial problems that parents have experienced already. Austerity also intensified the weaknesses in all schools' infrastructures. Participants finally suggested that the financial strangle that Greece experiences have contributed to the cultivation of a sense of 'lost hope'. The following quotes reflect the ideas suggested above:

"The lack of funds due to austerity has affected children with ASD. Their therapies are not approved anymore; they do not receive disability rates from the K.E.P.A. (Disability Certification Centre). At the age of austerity, disability rates have changed and hardly anyone gets a disability rate accordingly, so that they can have access to disability allowances. The disability allowance, of course, is not enough by any means to cover their therapies" (Professional 23).

"The lack of funds due to austerity has affected these children. Not that there were previously more funds, there were funds but there was no infrastructure both in Greek mainstream and special schools. But if there was a hope in the previous years, now it has disappeared, as well. Now because of the financial difficulties, whatever they ask for, it is not provided to schools" (Professional 35).

Professionals in this study refuted that the notion that austerity has influenced their professionalism and commitment to the ASD children. At the same time, they admitted that financial difficulties have made them feel uncertain about the future and negatively affected them emotionally. The following quotes demonstrate professionals' feelings:

"*My professionalism has not been affected by the economic crisis. Only psychologically I have been affected when I see what is happening around me, I don't know what will happen tomorrow" (Professional 12).*

"My professional ability hasn't been affected by the financial crisis. That is even if I earned twice as much money, I wouldn't have done anything more than what I do" (Professional 29).

4.13.2 Systemic Victimization of parents and children with ASD

4.13.2.1 Emotional Burden

Participants indicated that they felt victims of the current situation in Greece. They seemed to feel that because they carry the emotional burden alone they might not be as assertive as they need to be when fighting for their children's needs. Thirteen out of the twenty parents who were interviewed claimed that they shared a feeling of victimization and helplessness. These suggestions are reflected below:

"I believe what we are victims of the situation in our country, because we, as parents of SEN children, constitute a minority in Greece and none of us makes a fuss. In our country, they cut pensions, the rights people acquired after much fighting and nobody complained and it happened in 100% of the country. Now they've cut allowances and the provision of services for people with special educational needs by 10%, how will these people manage? Concerning special education, these children cannot assert their rights, we as their parents must fight for them. But many of us feel ashamed, we still cover up our child's deficit inside the house, we understate our problems and are not assertive" (Parent E).

"As parents of children with ASD, we have to become scientists, when we are not. We learn that our child has autism and we must offer him some treatment. In Greece, there is no structure, it is necessary for the parent to pull the rabbit out of the hat. Why? I feel indignant. Did the parent study autism? No, he didn't and he does not know anything about it. The parent has to be parent, teacher, escort/companion and speech and language therapist, all in one! In Greece, the emotional burden is borne by the parent but parent's counseling knowledge is very limited, because the treatment for his child was very expensive before the crisis. Crazy amounts they lifted the bar of access to help very high" (Parent M).

4.13.2.2 Legislation gaps in Special Education

Professionals suggested that despite the work that has been placed there are still several legislation gaps that negatively influence every day practical issues for parents and professionals. Professionals also argued that clarification is necessary in the issue of welfare entitlement as well as the nature of education ASD children receive. Finally, professionals also mentioned that since training regarding autism evolves, state should offer them the opportunity for further training and material in order to fulfill their duties effectively. These ideas suggested below:

"The legislation offers a general framework giving sometimes priority to children with autism, in the case of parallel support organizing a Special Assistant. At the same time issues that arise on daily practices need to be specialized in specific ministerial circulars" (Professional 2).

"I have been watching the legislation for many years, I have noticed that it has not changed anything, whereas training is progressing and evolving all the time. We're a little unsuspended. I think there should be a clear Curriculum (it does not exist) and more available material so that we can use and more training to be allocated" (Professional 15).

"In the current Greek legislation of special education there are several gaps, like in all things relating to the welfare and special education, which involve the institutions, the proper support which these children should accept" (Professional 37).

Interviewees recognized the need for communication between parents and the state to be based on trust and guidance. At the same time, participants claimed that something like this seemed difficult to be achieved given the element of intense bureaucracy that strongly influences all work related issues regarding public sector. The following quotes reflect the ideas suggested above:

"There must be mutual understanding between parents and the state. The parent is the centre of the attention. There must be someone to give the right direction over the treatment programme and the public body. There should be a trustworthy public body. Nobody told them what to do when their child was two years old and now they spend valuable time" (Professional 8).

"I cannot separate the work issues from the law in special education. The changes that occur in recent years relate to the whole of the public sector. These changes have made, somehow, these public services very selective and bureaucratic services to citizens. So special education de facto cannot be excluded from this context. And this situation is crucial even in the way we work, because once, -I'll give you an example,- the substitutes are not available from the beginning of the school year, and since we do not have building autonomy, these issues, even if we want to ignore them, define our day" (Professional 14).

Interviewees further suggested that although the Special Education Law offers clear suggestions in relation to a number of work related issues the implementation of them is rather difficult. Professionals claimed that although they strive to offer

legitimate services, improvisation takes place due to lack of resources and personnel. They always try to do what is best for the children even if that means not following the letter of the law. Moreover, professionals claimed that some issues raised within the legislative framework need further clarity. As an example they mentioned the case of EDEAY (Diagnostic and Evaluation Committee on Educational support). For these reasons participants suggested that the impact that the law has upon practice remains rather limited. The following extracts highlight the ideas presented above:

"I follow my experience and my schedule on the basis of the students' needs of each school. Certainly the law plays a big role; we strive to be legitimate in all aspects of our work. Implementing the law determines things greatly, but at the same time there is improvisation" (Professional 11).

"The special education law of 2008 is quite clear about the ratio between children with ASD and practitioners. It is suggested that up to three children can be looked after by one practitioner. But this is not something that is actually implemented in practice. The ratio between children and therapist is always larger. The law also clearly refers to the special educational support staff and what is recommended once again it is not implemented. While the theoretical framework of the law is quite comprehensive there are always problems with the implementation of it. As a result the impact that the law has in practice remains actually limited" (Professional 27).

"Also from last year, that EDEAY has worked, there is a small problem. It doesn't clearly define what happens in case that the position can't be covered by a deputy colleague. For example last year I had to cover this position for the needs of EDEAY. I think it is a serious issue for this position of EDEAY to be covered by a permanent psychologist" (Professional 32)

4.13.3 Making SEN policy effective

Parents and professionals seemed to have a clear understanding about the nature of changes that need to take place in order for the current educational policy to become effective. More specifically they seemed to be in favour of direct cooperation of the interdisciplinary teams that are necessary in order for children with ASD to receive the

best quality of services. At the same time they indicate the need for clearer educational legislative framework that meets the needs of the children. The following quotes highlight the ideas suggested above:

"First of all, there should be a single system approach and direct cooperation liaison of the ministries involved, i.e. health and education, and now and the Ministry of labour. This way interdisciplinary committees with a psychologist, a social worker and a teacher and in special schools, and perhaps with a speech therapist, will be able to function in order to help these children effectively"(Professional 16).

"I think there are shortcomings upon what should be done on the field. There are no educational frameworks for children as they can go to a school. They consider that it is specialized for autism. Certainly there is lack in legislation but mainly work needs to be done in relation to the educational legislative framework. The children with autism can't go in the same educational setting which there is other children with other difficulties since these children demonstrate specific difficulties that need to be taken into consideration" (Professional 24).

4.13.5 Awareness about services and support

Public services offered help and information and had an overall advisory role. On the other hand what parents seemed to want is guidance in finding the appropriate support for their child. These ideas are presented below:

"First of all there are fewer private or public centers for ASD and we didn't find any qualified staff. I began slowly to understand about the experts and professionals in ASD" (Parent S).

"I had a hard time finding an appropriate private or state center for my child, because I was ignorant. In prenatal testing there is a warning about what might be waiting for a mother, but I wasn't informed about my child's ASD. So, when we got the ASD diagnosis after two years I didn't know who to turn to or how to deal with this situation. There are cases of exploitation, when a doctor makes the diagnosis, he writes a lot of deficits, in order to claim the biggest package of services and sends the parents to his

own center. Finally a public service (I.K.A.) helped me and informed me about ASD. They told me that the center that the doctor recommended, was not very good, because many mothers reported that to them. But eventually I found a center and one lovely lady helped my child and I said I should apply for an education setting for him. This lady suggested to us an occupational therapist and we started to educate my child about daily life at home and things went very well. We didn't change professionals and it was very positive that my child was educated in a stable environment and with familiar faces" (Parent N).

"The first guidance that I got was from the special therapy unit for children with ASD (ETHMA) to help my child sort out daily problems. The first advice was on how to help my child to do what he was told, I got from ETHMA. This centre helped me to find ways to support my child" (Parent B).

Participants argued that Centers for Differential Diagnosis and Support of Special Educational Needs (K.E.D.D.Y) did not offer as much as parents expected. Parents also claimed that as a public service (K.E.D.D.Y) tries to cut costs. This means that the service does not offer parallel support to the children even if parents think of it as a necessity. Another issue raised by participants is that the professionals with whom parents and children have to work together with change and this did not help in creating the sense stability and security that it is important for their condition. Finally participants mentioned that (K.E.D.D.Y) is expected to help children who suffer from different conditions something that parents find that makes the situation even harder than it already is. The following interview extracts reflect the ideas suggested above:

"The KEDDY is a great difficulty. The role of these bodies should be advisory and consultative. We feel that the state has intervened decisively in KEDDY and driven away great scientists and so only those obedient to the partisan organs, stayed and were given a mandate to make cuts in order to rise professionally. For example, giving little parallel support, expelling our children from schools. The level of KEDDY functioning is frustrating to obscene. Essentially, they guide diagnoses in order not to give parallel support. The partial parallel support which has been institutionalized basically does not help the child, because it creates a changeable environment, not the fixed secure one necessary for an autistic child. These frequent changes are harmful and cruel for the

child and affect their mental stability and so these children cannot be educated properly" (Parent Q).

"The public centres are basically special schools or integrated with support centers (K.E.D.D.Y.) and these are completely unsuitable because they are adapted to deal with the mentally retarded and have nothing to do with autism. In Greece, autism has been linked to the data of learning disability/mental retardation, and the scientists know that and they foist that on us" (*Parent D).*

4.14 Parents' Views about ASD educational provision and services

Parents were asked to rate the importance of educational provision for children with ASD in particular. Over half indicated that they had encountered a degree of consensus on ASD services among professionals regarding educational services. Furthermore, more than half stated that they had an IEP in place and almost all parents reported that an IEP provided by schools was very important/ important. The vast majority of the participants reported that this was very important or important (94.3%), with the rest considering it slightly important. Over half of the parents stated that an ASD oriented curriculum was in place. Moreover, parents were asked to rate the importance of having an ASD oriented curriculum, and over half of them reported that their school offered this to certain extent. Furthermore, almost all parents rated that attendance at a special school unit was very important/important for their children. Half of parents stated that their children with ASD's attendance at this kind of unit was successful. In addition, over half of the parents reported that their ASD children's attendance at a mainstream school was important/very important, and almost half stated that this form of attendance was achieved. Likewise, when parents were asked about the importance of attendance at specialist education programmes, more than half rated this as very important. Around half the parents reported that their need for this kind of education programmes were partially met (see Table 4-38).

Table 4-38: Percentage (%) of Parents' views on ASD educational services and the importance to which these services were met

	Not Important/ Slightly	Important	Very important	Unmet	Partly Met	Met

	Important					
Professionals' consensus on the best ways to help ASD children on ASD services	6.8	39.7	53.4	20.5	58.9	20.5
Individual Educational Plan		38.0	62.0	25.0	56.9	18.1
ASD curriculum	5.7	44.3	50.0	23.6	56.9	19.4
Special school	5.5	45.2	49.3	15.3	34.7	50.0
Mainstream school	12.2	55.4	32.4	16.7	37.5	45.8
Attendance	9.7	34.7	55.6	37.0	47.9	15.1

There were no gender differences regarding the parents' views on ASD related services. This suggests that mothers and fathers shared similar views on these. However, the mothers rated the importance of access to an Individual Education Plan higher than the fathers. There were no statistically significant differences in parent views on ASD services as a function of education. However, parents with a higher education tended to rate having a school programme based on an ASD curriculum more highly than parents with compulsory education only (see Table 4-39).

Table 4-39: Parents' views on educational services by gender and education

	M(SD)	M(SD)	T	M(SD)	M(SD)	T
	Mother	**Father**		**Compulsory**	**Higher**	
Professionals' consensus on ASD services	2.51(.57)	2.36(.72)	2.53	2.58(.60)	2.35(.63)	.19
Individual Educational Plan	2.67(.47)	2.50(.51)	2.92	2.63(.49)	2.61(.49)	.08
ASD curriculum	2.52(.58)	2.27(.63)	.02	2.37(.59)	2.51(.61)	.08
Special school education	2.47(.54)	2.36(.72)	4.77	2.47(.56)	2.41(.64)	.95
Mainstream school education	2.19(.68)	2.23(.52)	2.15	2.24(.64)	2.16(.64)	.14
Attendance of education program	2.56(.67)	2.23(6.1)	1.06	2.47(.65)	2.44(.69)	.20

*p<.05 **p<.01 *** p<.001

N=22-52 N=35-37

As shown in Table 4-40, parents expressed their agreement or disagreement regarding the perceived benefits gained from their child's education provision in cognitive, emotional and social development. Most parents were of the view that there were benefits particularly in terms of their relationship with their children.

Table 4-40: Percentage (%) of Parents' perceived benefits from education provision

Improvement in:	Agree	Disagree
Parents' relationship with their child	91.8	8.2
Child's cognitive development	85.7	14.3
Child's adaptive, emotional and social development (e.g. friendships, social networking)	73.9	26.1
ASD child being accepted by others	73.6	26.4

Most parents did not consider remedial programmes to be useful and around half reported satisfaction with behaviour therapy, occupational therapy and speech and language therapy (see Table 4-41).

Table 4-41: Percentage (%) of Parent ratings on remedial services

Usefulness of remedial services	Somewhat Useful	Useful	Highly Useful
Occupational therapy	30.0	42.9	27.1
Speech and language therapy	40.3	41.7	18.1
Music Therapy	60.7	23.0	16.4
Structured Teaching TEACCH	51.6	34.4	14.1
Individual Educational Plan(I.E.P.)	50.0	36.1	13.9
Symbolic play	58.2	28.4	13.4
Sensory integration	54.3	34.3	11.4
Applied Behavioural Analysis(ABA)	68.3	20.6	11.1
Behaviour Therapy	40.6	49.3	10.1
Social stories	69.8	20.6	9.5
Picture exchange communication system	53.8	38.5	7.7
Social integration	68.5	26.0	5.5

There were no gender differences regarding parents' perceived usefulness of remedial services in that both mothers and fathers rated them highly. However, fathers tended to rate higher services that aim to support social integration, symbolic play and speech and language, while mothers were more satisfied with the following services: sensory integration, behavioural therapy, individual educational plans (IEP), picture exchange communication system (PECS), applied behavioural analysis (ABA), structured teaching (TEACCH), social stories, occupational therapy and music therapy. Differences were found in parents' ratings of sensory integration [t(52)=0.24, p.03, d.30], with parents with compulsory education only expressing lower satisfaction than

those with higher education level. The parents with compulsory education rated higher "TEACCH" and Behaviour therapy (see Table 4-42).

Table 4-42: Parents' perceived usefulness of remedial services by gender-education

	M(SD)	M(SD)	t	M(SD)	M(SD)	T
Satisfaction with	**Mother**	**Father**		**Compulsory Education**	**Higher Education**	
Social Integration	1.35(.59)	1.41(.59)	.08	1.32(.58)	1.42(.60)	.08
Sensory Integration	1.60(.70)	1.50(.67)	.24	1.47(.69)	1.68(.68)	.24* (d=30)
Behaviour therapy	1.75(.66)	1.57(.59)	.04	1.77(.59)	1.62(.69)	.04
Individual Educational Program(I.E.P.)	1.68(.74)	1.55(.67)	.49	1.53(.65)	1.75(.77)	.49
Picture Exchange Communication System(PECS)	1.57(.65)	1.47(.61)	.33	1.52(.68)	1.56(.60)	.60
Applied Behavioural Analysis(ABA)	1.47(.72)	1.33(.59)	2.04	1.43(.67)	1.42(.70)	.02
Structured teaching "TEACCH"	1.68(.74)	1.50(.68)	.32	1.66(.74)	1.59(.71)	.10
Social stories	1.41(.65)	1.37(.68)	.02	1.31(.64)	1.48(.67)	1.30
Symbolic Play	1.52(.72)	1.62(.74)	.02	1.44(.70)	1.67(.73)	.34
Speech and Language Therapy	1.76(.77)	1.82(.66)	2.33	1.75(.77)	1.81(.71)	.89
Occupational Therapy	2.02(.81)	1.86(.64)	2.37	1.97(.77)	1.97(.75)	.04
Music Therapy	1.57(.75)	1.53(.80)	.01	1.50(.77)	1.61(.76)	.00

*p<.05 **p<.01 *** p<.001

N= 17 – 51 N= 29 -37

Effective cooperation between specialties and better communication between Ministries was said to have the potential to enhance the quality of provision offered to children with ASD. Interviewees were also clear in suggested that ASD children would benefit from services that improve their social skills or help them adapt to society. Finally they acknowledged the need for a mutual understanding between state and parents who in turn seemed to need a helping hand with practical everyday issues. The following quotes reflect the ideas suggested above:

"*I think that every Ministry follows its own independent approach, and that makes the provision of adequate and quality services for these children and their families difficult. We need a multidisciplinary approach, cross-sectional and inter- ministerial. There must be a national coordination body that will help the link of all these structures, in the political consolidation and in a national planning and programming in order to support these children and their families"(Professional 23).*

"There is a need for more special education and training in the evening and in the weekends aiming at children being engaged in activities. The aim remains helping children become more accepted by society and improve their socialization skills. The parents do not need more money but they need solution to everyday issues, such as treatment. There is not a setting for a child in crisis for example in order to balance the medication" (Professional 36).

The responses that participants offered indicate that the accessibility and effectiveness of services related to ASD is influenced by many factors such as: lack of permanent personnel, professional's knowledge and expertise on ASD, professionals' commitment on their work, as well as the way each child would respond to professionals' approach. Interviewees also suggested that parents' attitudes and expectations from the professionals might lead to a negative evaluation of the services offered. Finally professionals seemed to suggest that their duties and responsibilities in a centre might extend far beyond the scope of their role and that hinder their effectiveness. The following extracts reflect the ideas suggested above:

"With regards to evaluation, it depends on the expert. I believe that the professional must have the energy, character and passion to develop the individual. Naturally it is a matter of the possibilities of the child. I can't either praise or blame any expert if my child is not in the mood to receive and accept help" (Parent K).

"They have the goodwill. We meet mainly young people at schools who are willing. However, in special schools, the problem is that teachers are not permanent there and so, things are difficult for our children" (Parent R).

"Experts do not always have the appropriate skills to meet the challenges of my child, it always depends on the person. There are people who are responsible enough to the point of extreme self-sacrifice and there are people who just want to escape responsibility" (Parent E).

"*Professionals aren't given the responsibility. Unfortunately the establishment functions in such a way that it doesn't let the therapists work in a range of different ways. The centres are asking for fixed programmes, such as teaching, so experts are directed only to them and not to any other concerns (feeding etc.). The parents' themselves are the problem. They want to hand their child over to the therapist so he will 'fix' it. This is not going to happen unless the parent is involved in everything" (Parent S).*

Parents suggested that professionals lent a helping hand and offered guidance when parents needed it most. At the same time, parents suggested the majority of professionals lack education and expertise on ASD. For parents experience in the field comes when professionals put time and effort in helping their children. At the same time, professionals claimed that the nature of their work makes personal commitment to the benefit of children a prerequisite. Finally, they also acknowledged that the necessity of continuous and specialized training in order to be even more effective in their work. Illustrative quotes reflect the ideas suggested above:

"The experts help me, so that I can access other opinions when I feel blocked in by something. You are given more options, and then you are so tired you cannot think anymore but a specialist can give you new information with his knowledge. They have indeed helped me sometimes to follow a different path. In the past, they attended a seminar that made them and a specialist in autism but you have to work hard all around this as to gain experience. There are experienced specialists but some of them are inexperienced and ignorant" (Parent N).

"Most of us have attended some seminars. This does not mean that they have acquired specialized knowledge. You can't be responsible for a child in the autistic spectrum, only with seminars. This thing is a crime. Everyone can achieve anything, we all know everything. You have to have fulfilled a training, a serious post-training not only seminars. Some teachers have only attended seminars and some others do far more

damage than benefit. You have to really want to work in special education" (Professional 30).

4.14.1 School Benefits for children with ASD and the Challenges of Inclusion

Participants in this study seemed to acknowledge that the combination of their intense efforts and the effectiveness of the structured programme that the school suggested had optimum result for their children. This is presented below:

"Our child benefited from the education program but also our contributions and especially my wife's who has ASD knowledge as a teacher had constructive cooperation with the teacher and the special parallel support teacher of my child" (*Parent F).*

"I can't deny that my child is what he is due to the education which he had until today. Clearly everyone has contributed to this result even myself, with a lot of effort to follow a structured programme for him" (Parent A).

Participants in this study seemed to suggest that it is difficult for inclusion to be implemented in everyday practice. Interviewees acknowledged that the resistance in that area may be due to ignorance. They also suggested that ASD children face practical difficulties due to lack of structures that would give them options to study after the completion of primary education. Finally, participants recognized the influence that family background has in the quality of children with ASD's school experience. The following quotes reflect the ideas suggested above:

"Although the term 'inclusion' is known in Greece we cannot implement it because there is an enormous resistance from specialists. When I say specialists I mean bodies like ours, head teachers and teachers. The problem is that there is a great resistance due to reasons of ignorance. However, as an educational community we must solve this issue right now in order to have a common line with parents" (Professional 13).

"You know that after the primary education the choices for these children are a few. There are only two to three contexts but they are not the best ones for autistic children. You have no alternative structures. It is a fact that sometimes these children do not have the family they need and this fact makes the situation even worse. We cannot ignore the social and economic conditions" (Professional 26).

Parents in this study preferred mainstream rather than special schools. Parents want their children to get a sense of 'fitting in' to the greatest possible extend and maintain a sense of normality. Finally, parents seemed to argue that their children attending a special school will be a step back in their progress. The following quotes reflect the ideas suggested above.

"The special needs schools are 'cocooned' and not able to equip my child with ASD with the skills necessary to go out into society. A mainstream school will give my child a better chance of fitting into society as she will learn social norms and what is and isn't acceptable and that this will help to integrate my child into society" (Parent O).

"I would like my child's life to be pretty much as normal as possible. As long as my child can cope in a mainstream environment that will still be the best bet. I want for him to be in the same school as typically developing children. So, surely, my goal would be to place my child in the most normal setting as possible." (Parent B)

"I won't put my child in a school for autism, as I don't not believe that my child will develop there. I will be failing as a mother if I did not do what was best for my child's potential" (Parent D).

4.14.2 Suggestions on Improvement in ASD services

Parents were very clear as to what in their opinion needed to be done in order to have efficient and effective services for their children. Specifically they suggested establishing all day schools and therapeutic programmes in the public sector. They also wished for early intervention services as well as infrastructures that will help their children to be independent. They finally seemed to be in favour of working with

specialists who show empathy to them and their children. Their suggestions are presented below:

"Firstly, parents of children with ASD must be heard. We want an all - day school, so each parent can work and contribute to his family's income. The all-day school should provide therapeutic programmes (sessions) in order not to have to resort to private centres. The shadow special education is very good. It should become a framework for adults. We should not rely solely on private initiatives" (Parent C).

"I want every region to have its own centre, where children to be educated at an early age, to communicate, to play sports without parents having to transport them. I would like to have this responsibility taken over at municipality level. Also, I would like the professionals to realize that showing empathy at work can mean getting great pleasure. The ASD children's world is magical and it's nice to be part of it" (Parent N).

"To make structures of support which are adaptable according to circumstances. There should be early intervention. These children should be diagnosed very early and then an immediate intervention to save time. There should be appropriate criteria and direct monitoring of the child and raising the child with ASD should be brought up to be independent both socially and professionally" (Parent S).

At the same time professionals suggested that clarity is necessary especially in relation to the legislative framework linked to the education of ASD children. They were equally clear in suggesting that central coordination and effective communication between disciplines is necessary. In the same line of argument effective cooperation with families is of equal importance. Finally professionals suggested that they need to work toward changing the society's approach to ASD to the extent that this is possible. These ideas are reflected below:

"I think there are shortcomings upon what should be done on the field. There are no educational frameworks for children as they can go to a school. They consider that it is specialized for autism. Certainly there is lack in legislation but mostly it is missing the educational context. The children with autism can't go in the same educational setting

which there are other children with other difficulties where are specific difficulties that these children have" (Professional 21).

"I think I need a central coordination. The operation and staffing of a service that will have representatives from each Ministry to deal with overall issues of children with autism and their families and not only with their education, their health or with social welfare. And there should be specialised scientists for each domain who would be located in a single unit for services" (Professional 34).

4.15 Key findings of the role of the state

For the state inclusion is a value laden umbrella term. Parents and professionals agreed that although the state recognizes ASD as a disability limited help is offered in the form of services benefits and treatments something that has intensified after 2008 due to the economic crisis which had a severe impact upon the services offered for children with ASD. Despite this parents and professionals are relatively satisfied by the quality of services regarding the diagnostic process. Parents indicated that they felt victims of the current situation in Greece. Because of the emotional burden they carry they might not be as assertive as they can for their children's needs. Parents' level of education influences their ability to access the appropriate services for their children as well as the way parents and children work together. Professionals suggested that they have to improvise in everyday practice due to lack of resources and personnel. As a result the impact of the law remains rather limited. Participants raised the issues of early intervention and lack of training for children with autism after the end of formal schooling. Parents also acknowledged the lack of therapeutic models for children in the public domain while professionals indicated the need for the services to be organized better and communicate more effectively if they are to become efficient. Public services should offer help and information and have an overall advisory role. Parents and professionals agreed on the existence of legislation gaps that influence negatively everyday practical issues. Communication between parents and the state should be based upon trust and guidance. Parents and professionals were very clear in recognizing the factors that affect accessibility and effectiveness regarding the provision offered to their children. They recognized a number of difficulties in this process ranging from lack of state funding and structures to lack of qualified permanent personnel and poor

quality public services for the children. Parents and professionals also recognized the need for further specialized training and less bureaucracy in relation to the acquisition of the treatments for the children and the financial benefit. Finally, professionals acknowledged need for clarity in the legislative framework, interdisciplinary cooperation and communication.

CHAPTER 5: Discussion

The aim of this study was to examine parents' and professionals' views on autism support and services in Greece as well as the challenges parents faced in supporting their children with ASD. Autism is a developmental disorder characterised and diagnosed by behavioural symptoms that indicate impairment in social and communication behaviour along with a restricted range of activities and interests (Makrygianni and Reed, 2010). Cullen and Barlow (2002) pointed out that the difficulty of diagnosis at birth, the broad spectrum of the disorders and the lack of consensus in relation to its definition are key reasons why the prevalence of autism is difficult to assess and the appropriate support difficult to obtain. Moen et al. (1995) argued that theoretically driven research was significant for Bronfenbrenner as science needs policy as much as policy needs science, because 'issues of social policy [serve] as points of departure for the identification of significant theoretical and scientific questions concerning the development of the human organism as a function of interaction with its enduring environment-both actual and potential' (Bronfenbrenner, 1974, in Moen et al. 1995, p. 4) With this in mind, the ecological model was used as a vehicle in this study to better understand issues related to autism in terms of policy and practice. An ecological perspective considers the reciprocal interaction between human development and the multiple environments in which it unfolds, which Bronfenbrenner referred to as the microsystem, mesosystem, exosystem, macrosystem, and chronosystem.

This study examined parental views and professionals' attitudes towards children with ASD, particularly their educational and social needs. The findings suggest that parents experience stress and anxiety about the future of their children, especially regarding the likelihood of their achieving an independent life. This concern influenced all aspects of parents' personal and professional lives and changed their priorities. Parents highlighted the need for professional and personal networks to provide social support and help them work through societal prejudice and stigma. Moreover, professionals clearly demonstrated their awareness of the challenges that parents of children with ASD face, varying from reaching for and achieving educational and social support to the emotions they experience when raising a child with significant communicative and social impairment. The professionals acknowledged the significance of parent collaboration in meeting ASD's children's needs. They also supported inter-professional collaboration but found it difficult to implement in practice.

When it finally came to working with parents, some of the professionals found it difficult to ensure that parents understood and agreed with their professional advice and expertise. Furthermore, parents and professionals seem to have similar clear views as to the necessary steps that should be taken by the state in order to offer quality provision to ASD children. Lack of state funding, structures and resources are some of the shortcomings recognized. Parents and professionals also acknowledged the need for more resources, training and access to permanent staff as well as the need for less bureaucracy in relation to sourcing treatment for children with ASD. Finally, the professionals acknowledged the need for clarity in the relevant legislation and Ministry directives and accepted that interdisciplinary cooperation and communication are effective in meeting ASD children's needs.

The findings of this study emerged from rich data obtained about parents' everyday experiences of living with a child with ASD and the knowledge they had acquired through trial and error, and from trained professionals in the field of Special Educational Needs (SEN) who had received formal training and had experience of working with children with ASD in special or mainstream schools or in other establishments in the public or private sector. On the basis of the data gathered, the key findings concerned: the challenges faced by parents in raising children with ASD, stigma and prejudice, social networks and systems of support, parent-professional collaboration and educational policy in a period of austerity. Differences of opinion were clearly expressed and wherever possible, comparison of the views held by the two groups of participants (parents and professionals) was presented.

It is clear from the research that the most affected by financial crisis and its devastating social consequences, are the economically weaker families, and those without social health insurance (which is linked to employment status), and who are unable to cover the cost of their child's therapy (Anagnostopoulos and Soumaki, 2013). In periods of economic crisis and extended recessions, while the demands on mental health services increase, but because of the reduction in health and social services expenditure, their provision progressively decreases. Families and children in such a situation seem to suffer from lack or lower quality services within the public sector; a huge bulk of psychological and psychiatric care can be obtained in the private sector but only by for those who can afford it.

According to Papageorgiou (2004) one area of research concerning parents and families in the field of autism is the effects of the child's condition on family members

and the role of parents in the treatment of the disorder. Bronfenbrenner's theory addressed the different layers of environmental influence that affect a child's development (Bronfenbrenner, 1979). The primary system that a child is surrounded by is known as their microsystem. This refers to the individuals that the child interacts with the most often. In the early years of life, the family is typically the primary environmental influence on a child. The more encouraging and nurturing environments are, the better the child will develop. In addition, every child's personality traits will influence how the child acts or reacts in the microsystem and how others will treat him/her in return. In Bronfenbrenner's theory, the child's development takes place through processes of progressively more complex interactions between an active child and the persons, and objects in his/her immediate environment. To be effective, the interaction must occur on a fairly regular basis over extended periods of time (Adapted from Bronfenbrenner, 1998, p. 996). Such enduring forms of interaction in the immediate environment are referred to as proximal processes. These have to do with what the child is doing and with whom. This model can be useful in explaining family dynamics when an ASD child is part of it as well as the potential impact of the family system on the parents or on typically developing children

Furthermore, Siklos and Kerns (2006) argued that autism is 'a pervasive developmental disorder that is characterized by deficiencies in social interaction, communication and restricted interests and activities'. Cunningham and Davis (1985) suggested that parents struggle to feel suitable and adequate in their role as caretakers and fear the possible negative effects that their decisions might have upon their children. For these reasons, the first section of this chapter will discuss the emotional challenges that parents face when caring for a child with ASD.

5.1 Parents' emotional challenges

Boudreau and Harvey (2013) have suggested that it is possible for autism to be diagnosed when an individual exhibits significant impairment in three broad areas: social interaction, communication, and general behaviour. The realization that the children will have impairments in significant areas of their behaviour seemed to have particularly intense pragmatic and emotional repercussions for parents in this study. They had to confront and work through a series of negative feelings. Parents' emotional challenges emerged as a key issue in this study. Bronfenbrenner's 1979b theory is

dynamic and describes developmental outcomes as a result of bidirectional interactions between individual personality traits and ecological contexts. Ravidran and Meyers (2012) argued that what makes Bronfenbrenner's ecological model useful for examining disability is that 'it reveals an interconnected system in which the influences at one level flow naturally into the other levels. Proximal levels work in conjunction with more distant influences in the macrosystem and the exosystem' (p.313). Influences in the microsystem have a direct impact upon a child's development. Parents' emotional challenges negatively affect the children's development. Parents seemed to agree with Gray (1993) who argued that the stress of living with autistic individuals can affect the psychological well-being of all family members (p.103). Wachtel and Carter (2008) also argued that when a child is diagnosed with ASD, their parents experience a range of feelings and a set of challenges that have an impact on their psychological adjustment. Parents' feelings ranged from relief because their suspicions were validated, to grief for the loss of the child they had envisioned. Parents' feelings in this study ranged from sadness and fear to despair.

These feelings were intensified, since in most cases, as experts informed parents that most adults with ASD are unemployed, friendless and do not live independent lives (Sigman et al. 2006, pp.339-340). Parents in this study were shocked, stressed, worried and undecided about how to plan the future of their children, especially when they will no longer be available to provide support.

Lilley (2013) pointed out that sometimes parents experience feelings of guilt or responsibility for the disability itself, which in turn, may make turn into feelings of aversion to it. The fact that parents look for answers regarding the cause or causes of their child's condition coupled with their inability to help him/her overcome the disorder may explain, to an extent, the feelings of guilt that parents and especially mothers experience which can often lead to social isolation. The participants in this study experienced intense feelings of stress and anxiety when asking why their child had the condition and how they could help him/her efficiently and effectively.

The findings of Estes et al. (2009) also indicated that mothers of children with ASD experienced higher stress levels compared to mothers of children with other developmental difficulties. Among the participants of this study, there were no gender differences in the ratings of the importance of support by their parents. However, compared to fathers, mothers were more likely to rate their need for reassurance more highly. This is a finding that can reasonably be attributed to the insecurity that mothers

tend to feel if they can't contribute to the their family finances as they usually bear the care of the autistic child and rely solely on the father in a relationship that may have been shaken by the situation and the needs of the child.

Morgan (1988) also argued that the parents of children with pervasive developmental disorders do not present a certain or single "reaction profile". The anxiety and stress they experience are associated with difficulties which, when accumulated, can cause fatigue, burnout, depression, which are exacerbated when appropriate therapeutic services are not on offer to either the parent or child. In this study, parents had difficulties in accepting the diagnosis (Sanders and Morgan, 1997). At the same time, they had to face their child's medical and developmental challenges and delays in the diagnosis of their child's condition.

In addition, the participants in this study claimed that they did not have time for themselves and their needs and they acknowledged that they found it hard to allow themselves to express such needs. Fathers experienced increased anxiety when the financial demands of child care not only forced them to work exhausting hours, but also deprived them of the time to take care of and have contact with their child (Rodrigue et al., 1992). The participants' responses in this study seemed to support the findings of the research conducted by Tunali and Power (2002), which suggested that mothers of children with developmental disorders often end their careers and have very little time for themselves. Often mothers were unemployed and had to rearrange their lives according to their children's needs.

Furthermore, according to Hastings (2002), the strength of the family unit and the ability to adapt in the face of difficulties becomes evident when the family has to deal with intense and stressful situations. Children with ASD present a wide range of symptoms and behaviours that can adversely affect the parents' as well as the wider family's health. Bebko et al. (1987) argued that the stress experienced in such families has a negative influence on family and intra familial relationships, as well as the social and emotional health of the parents. The participants in this study claimed that the immediate family members acted as the prime sources of support but the stress all members felt due to the child's condition seemed to be physically and emotionally exhausting and contributed to their social as well as emotional isolation.

Gray's research (2003) findings on parents of children with high functioning autism found different personal effects on the mothers than of the fathers of autistic

children. Although most fathers recognized the severe difficulties caused by the disorder, they usually claimed that the child's difficulties did not have a significant effect on their personality. This does not mean that the presence of a child with autism does not affect fathers but that the effect of the disorder was indirect. More mothers, on the other hand, stated that a child with autism significantly affected their emotional well-being. Perhaps this rationale explains why only 52% of the participants in this study acknowledged that they made changes in their lives personally and professionally in order to accommodate their child's needs. The findings of this study are consistent with those of Breitkreuz et al. (2014), who suggested that although there are theoretical frameworks such as stress and coping theory that regard misfortune as an inherent characteristic of the situation, my participants, while acknowledging considerable difficulties, make me rethink why this struggle takes place.

Parents in this study had positive feelings about their children and felt that their child's condition made them approach life and its challenges in a different way by focusing on calm and quality relationships. The findings also supported Breitkreuz et al.'s (2014) suggestions that significant complexity is to be expected in a family, and for that reason, studying this complexity is important. Stress and coping are considered inherent responses when studying disability and for that reason, the joys of raising a child with disabilities have been overlooked. Furthermore Green (2007) has suggested that in cases where emotional distress is experienced after the initial shock of the diagnosis, it will not be related to the child's disability but to the perception that disabled people are stigmatized by others in the community.

The next section of the discussion focuses on parents' views of the stigma and societal prejudice associated with raising a child with ASD and what this meant for their relationship with professionals.

5.2 Societal Stigma and Prejudice

Experience of stigma associated with Autism Spectrum Disorders (ASD) was found to be widespread among families with children with ASD. Kinnear et al. (2016) suggested the need for research with parents of children with ASD in order to further understand the impact stigma has on their lives. Stigma is a multifaceted construct defined by (Goffman 1986[1963]) as 'deeply discrediting since it reduces the individual from a whole person to a tainted, discounted one' (p.3). Goffman (1986) [1963] argued

that stigma is the result of attributes that do not fit the normative expectations of a society and produce a defective social identity for the individual or the group who possess the attributes. Broady et al., (2017) stated that despite growing evidence base regarding autism spectrum disorders and their increasing prevalence, children on the autism spectrum and their families continue to perceive they are stigmatised from various sources throughout the community.

Bronfenbrenner (1995) argued that the 'form power content and direction of the proximal processes vary systematically as a joint function of the biological characteristics of the developing person and the environment immediate or remote in which the processes are taking place' (p.621). 'What is important about proximal processes is their significance as a mechanism of organism - environment behavioural interactions that drive development and the ways in which these mechanisms are affected by the characteristics of the developing person and the environmental context in which the interaction takes place' (p.626). With this in mind, stigma is considered as a source of negative influence on the quality of interaction since it affects the individual interpersonally and interpersonally.

Green et al., (2005) discussing Link and Phelan's (2001) components of stigma, referred to *labeling*, which she defined as the recognition of differences and the assignment of social silence to those differences. In the context of disability 'it is the recognition that a biological trait differs in ways that have social significance' (p.197). Green et al. (2005) went on to define *stereotyping* as the attribution of a negative value to socially silenced differences.

Parents in this study claimed that their children behaved in ways that deviated from age appropriate developmental experiences. They acknowledged that the child they now had to raise was 'different to the one they gave birth to' suggesting that parents' may view their child as a transgressor of the dominant ideas of normal behaviour (Huws and Jones, 2010).

Participants in this study claimed that they feel inadequate in their role as parents since their child could not achieve "the persuasive grip" of the standardized child (James, 2005, pp.102-103) and also because they focused their attention on the ASD child, neglecting siblings.

"*I experienced a mournful situation. I came to a point where I was jealous of my own children on behalf of my child with ASD. This was a serious issue so I wasn't interested*

in my other children and didn't pay attention to my husband's needs. I didn't care about my needs either. I was absorbed with my son. I lived in a very depressing situation. I slept and woke up with his image. I tried to find solutions for him. I started recovering when I saw some progress. My son was my hope" (Parent B).

Some parents experienced marginalization stemming from the fact that their children would never reach the expected childhood milestones. They felt they belonged to a group of "us against the rest" where parents had to act as mediators for their children (Lilley, 2013) to minimize societal stigma.

Bronfenbrenner's model is a useful tool for understanding how stigma is a 'negative external influence affects the capability of parents to foster the healthy development of their children' (Berry, 1995, p.379). Examining the influence of stigma does not stop with the members of the immediate family as significant others (Mead 1934, in Bronfenbrenner, 1995, p.638) because Bronfenbrenner's model acknowledges that the family is part of a much broader complex of systems. The mesosystem involves, according to Berry (1995), 'interrelations between the family and other settings including the child's school, the parents' workplace extended family friends and neighbors' (p.380). The belief systems of those who are part of the mesosystem might, according to Bronfenbrenner (1995), function as the 'instigator and maintainer of reciprocal interaction with the developing person' (p.638). Bronfenbrenner's (1979) conceptualization suggests that the level of understanding one has of autism ultimately interacts with and influences any stigmatizing thoughts and behaviour towards families with ASD children.

Moreover, Gray (1993), referring to the work of Goffman (1986) [1963] when he made a further distinction between courtesy stigma and stigma by association, which relates to those who voluntarily associate with stigmatized individuals. Lilley (2013) included parents among the circle of people whom she calls "wise" in the sense that they are 'intimate with and privy to the daily lives and social worlds of those who are stigmatized' (p.4) and become themselves stigmatized through this connection. Gray (2002) found that stigma by association applies to the parents of children with autism and highlighted the characteristics of the situation that created stereotypes based on the external appearance of autistic children - not the reality of their condition. The distinctive, disruptive, and socially inappropriate behaviour that children with ASD exhibit and the hardship that parents experience in order to receive an accurate diagnosis contributed to their feelings of stigmatisation.

Furthermore, Gray (1993, 2002) studied courtesy stigma (public disapproval) amongst parents of children diagnosed with autism. He argued that mothers experience stronger feelings of stigmatization partly because they 'take greater responsibility for the public presentation of the family' (Gray 1993, p.114). Green (2003) also suggested that 'the degree of stigma expected by mothers has an impact on emotional and social outcomes for themselves and their children' (p.1371). At the same time, Brobst et al. (2009) suggested that despite a variety of common research themes regarding the difficulties involved in parenting a child with special needs, including a decrease in the fathers' involvement in child care. Although the intensity of stigmatization is not clearly different between the sexes, the findings in this study show that the majority of those who acted as prime caregivers were mothers who had completed studies at university level.

Parish et al. (2004) pointed out that children with developmental disabilities have a range of needs. These include: specialized therapies, respite care for careers, lengthy diagnostic tests, home modifications, and adaptive equipment, medication, and education services. This entails financial difficulties and loss of jobs as well as the inability of parents to find time for their personal needs. Link and Phelan (2001) discussed stigma in the context of power differential and presented five equally important and interrelated components. One of these is the loss of status when stigma influences the ability of the individual to fully participate in the social and economic life of their community. Parents in this study may have experienced status loss since they admitted that they had to reorganize their lives in accordance with their child's needs. In practice, this meant reduced or no working hours and the corresponding loss of earnings and significant influences on every aspect of family life. Poston et al. (2003) defined family as 'people who think of themselves [as] part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis' (p. 319). At the same time, Grolin et al. (2016) discussed the concept of hybrid families of both nuclear and extended families and friends as a way of achieving physical and emotional support. The definition of family provided by Poston et al. (2003) as well as the term of the hybrid Grolin et al (2016) have similarities to the concept of extended family as understood within the Greek culture.

Andonopoulou (2011) suggested that the Greek traditional extended family is the cornerstone of the community. One of the principle roles of this type of family was and still is to develop in its members a strong sense of belonging based upon the principles

of interdependence, mutual assistance and solidarity. Grandparents play an important role in raising their grandchildren by offering help, support and guidance to their parents whenever required during the process of child rearing. Andonopoulou (2011) seemed to agree with the view of Kyriakidis (1997) who argued that the family should be approached as a ‘‘whole’’ network of people, rather than the number of members it consists of. In essence, it is a functioning system of people who are related and interact with each other within well-defined relationships governed by a certain dynamic. The welfare of the family members is the main priority and the principle is all for one and one for all, especially in times of necessity.

In this line of argument, when a family deals with a difficult and sensitive situation, it is usual for the extended family to provide support. Hornby and Ashworth (1994) suggested that grandparents might be either a source of support or a source of stress for the family. The findings of this study indicated that grandparents and the extended family had a supportive role. If they choose to be supportive they can be invaluable for the parents in their efforts to navigate through the problems of everyday life. Hamillton (2007) argued that emotional support is offered through listening empathy and friendship. Practical support is given through care giving duties for ‘respite care and work-related activities, monetary support, transportation, assistance with medical appointments and behavioural problems, help with household chores, regular visits’ (p.516).

However, if they do not understand the situation or deny the child’s disability in an attempt to avoid pain, they can intensify the difficulties. Notas (2005) went one step further, claiming that the negative attitude of grandparents and relatives can range from less constructive to damaging. They might argue that a child with autism stigmatizes the whole family. In everyday life, this might result in stopping seeing the child or not considering him or her as part of the family. Another approach could be, according to Notas (2005), denying the problem as a whole and claiming that all the problems that parents face is the result of the way they chose to raise their children.

The findings of this study seem to agree with Green’s (2001) view of the concept of “normalization”. Green (2001) argued that when grandparents [and in this study, extended family] were able to play ‘the grandparent roles characteristic of their familial and cultural heritage, they may help parents to see their parenting roles as part of the normal pattern of intergenerational relations despite the less than usual nature of these roles—thus supporting “normalization” and parental well-being’ (p. 14). The findings

of this study suggest that grandparents and the rest of the extended family were in need of help themselves in order to adjust to their circumstances. Despite this, they formed a social support network for the parents in the sense that they helped them maintain family relationships. The data collected indicated a 'clear need for social support in relation to the stressors of autism in their family' (Hamillton , 2007, p.518).

Parents seemed to agree with Lilley's (2013) argument that part of the problem lies with the inadequate state support and services for the developmentally disabled and the consequent need for one parent to be constantly available for caregiving negotiation with services and advocacy of their child's needs.

The findings in this study show that parents experienced courtesy stigma since their responses show that they had experienced intensely all the features indicated in Gray's (2002) research. More specifically,

"*Some people treat him in a strange way. Some others ignore him and they don't care about him. They are cautious and incredulous and it is really difficult for them to understand that he has qualifications and skills but they must show a little patience to discover them" (Parent L).*

The parents' responses in this study seemed to support the findings of Farrugia (2009) who discussed parent-child relationships in terms of disability as well as autism. Farrugia (2009) argued that due to their child's diagnosis, parents have difficulty connecting with their child, while at the same time, they want to detach themselves from feeling that they have "a spoiled identity". Parents in this study indicated that they had to find new ways of communicating with their children while at the same time had to fight to feel 'normal but different' Gray (1993) themselves.

Green et al. (2005) offered Susman's (1994) definition of stigma as 'an adverse reaction to the perception of a negatively evaluated difference' (p.197). As such stigma has to do with the interaction between the stigmatized individual and those who evaluate difference negatively. Green (2003) referred to this as "the subjective burden of stigmatization" and suggests it relates to the feelings that caregivers experience as a result of coping with the reactions of others to children with disability. Green referred to a range of emotions including among others: 'embarrassment, guilt, shame, resentment, entrapment, worry' (2003, p.1364). The results of this study seemed to indicate that the

parents of children with ASD felt "internal turmoil experienced on a regular basis" (Green 2003, p.1366) as a result of dealing with the subjective burden of stigmatization and the everyday tasks required to care for their children.

"*We had to deal with our child's vicissitudes. There was no progress, no hope, no joy, and no communication. We were almost ready to give up. We had lost all hope and we faced serious depression. We thought we couldn't succeed" (Parent M).*

"*Our emotions were simple: unhappiness and devastation. On the other hand, we were determined to help our child so we didn't grumble. We just wanted to help our child and improve my communication with him" (Parent P).*

Parents in this study argued that they were labeled and stereotyped by their social circle. In order to respond to these behaviours and limit social awkwardness, the participants in this study tried to be frank and educate "others" about their child's condition.

Furthermore, Link and Phelan (2001) suggested that the sources and targets of stigmatization are two different concepts and both are socially situated. They offered another description of the concept of stigma: *felt* and *enacted* stigma. Felt stigma relates to the feelings associated with having a socially undesirable attitude while enacted stigma relates to episodes of discrimination against people with a stigmatizing attribute. Parker and Aggleton, (2003) suggested that enacted stigma is a means of producing and reproducing the existing social hierarchies, and that resisting or negotiating the experience of felt stigma is a means of challenging these hierarchies. The results of this study show that parents experienced both felt and enacted stigma due to their child's condition. The parents seemed to also subscribe to the notion of "structural discrimination" (Link and Phelan, 2006) when they tried to enroll their child at school. They faced a form of school exclusion for their children on the basis that the school they wanted their children to attend did not have the resources to help their children but also because of the prejudicial attitudes of other parents. These forms of attempted exclusion occur with sufficient frequency to constitute accumulated practices that work to the disadvantage of children with ASD (Link and Phelan 2001, cited in Linley, 2013).

"I experienced my child's stigma in a private kindergarten. It was the first slap. I experienced racism, when the teacher told me that my child would not participate in the school's celebration because the other parents would be upset. I tried to protect my child. I moved him to a public kindergarten where the environment was more appropriate because the teachers accepted him. I did everything to forestall the difficulties and the other parents' reactions at that school" (Parent F).

In examining the experience of stigma, definitions of stigma are useful. The parents in this study experienced enacted and courtesy stigma. Finally, the researcher subscribes to the notion that stigma is the result of a process where five interrelated components combine to generate stigma, namely labeling, stereotyping, status loss and discrimination. The next section discusses the extent to which the condition of a child with ASD influences the social relationships and life of parents.

5.3 Formal and informal social networks

Cullen and Barlow (2002) argued that parents find it very difficult to come to terms with their children's lack of interaction and this realization can bring to the foreground feelings of helplessness and frustration and also difficulties with social interactions. Participants in this study clearly suggested that their child's inability to interact effectively with others had a significant influence on the overall life of the family and especially the family's social life. Bronfenbrenner (1979) portrayed the environment as 'a set of nested structures, each inside the next, like a set of Russian dolls' (p.3) with developmental emphasis placed on the relationships and interconnections between each individual and his or her settings. Bronfenbrenner (1986 in Sontag, 1996) identified three exosystems that are most likely to influence the family 'a) parents' workplace b) parents social networks and c) community influences' (p.330). Social support in the form of formal and informal networks can be seen as part of the exosystem.

Parents claimed that social support could be a helping hand for their attempts to deal with the stress and the sense of imbalance in their family that they experience as a result of their child's condition. They were in favour of respite-care or athletic and creative activities which would motivate their children to partake in the social life of the community. Social support has been defined as information that makes the individual

feel valued and appreciated in a network of mutual obligation and communication (Siklos and Kerns, 2006, p.921). Dunst and Trivette (1990) referred to two types of social support systems: *informal and formal.* Informal support systems refer to the relationships between family members, relatives, neighbours, friends, and community groups. Formal support systems are the services provided by professionals such as school programs, parent education specialists, therapists, and respite-care agencies. According to Sharpley et al. (1997) concern over the permanency of a child's condition, poor acceptance of autistic behaviours from parents and society, as well as low levels of social support for parents can be considered one of the stressful factors associated with parenting a child with autism. Family problems as a result of the condition, according to Harris (1984), include marital conflict, high divorce rates, financial problems and conflicts between parents and their other children. Mendoza and Dickson (2010) also argued that 'social support can act as a buffer against the demands of raising a child with developmental disabilities' (p.13).

Boyed (2002) has suggested that the ability of social support to serve as a stress mediator depends upon gender. It has been found to contribute to lowering maternal stress, while the contribution was not significant as far as fathers were concerned. Mothers in this study seemed to concur with Boyd (2002) who suggested that the mothers of autistic children turned first for informal support to their husbands to relatives and other parents of children with developmental disabilities. The parents in this study although they recognized the risk of neglecting their marriage when they had a child with disabilities (Piven et al., 1991), seemed determined to keep their marriage strong (Pelchat et al., 2003).

Sharpley et al. (1997) argued that the most common form of "respite" from everyday parenting is through informal networks namely, grandparents, aunts, uncles, and siblings whom of the parents children with autism look primarily to for social and emotional support. The participants in this study turned to their immediate and extended family for social support but at the same time claimed that the nature and the value of the social support they received left them by and large unsatisfied. The findings of this study indicate that especially the members of the extended family did not know how to help parents although the intention to help was there. Sharpley et al. (1997) argued that there might be a link between the perceived level of understanding that parents felt that their assisting family members had about their child's condition, and their efficacy as parents. If relatives and extended family perceived the parents as being experts in

handling the child's problems, this would help strengthen the belief that parents themselves were able to work through the problems without needing extra support.

In addition, Callias (1997) also argued that parents may be overprotective due to a lack of trust in the child's abilities and fear of exposing the child to unknown social situations. This can result in excluding the child from the social and emotional experiences necessary to facilitate his/her integration into school initially, and then to the wider social context. The participants in this study although they realized that the condition of their child would demand from them a life time of care, expressed feelings of love and acceptance of their child. At the same time, they claimed that they had tried to include their child in all their social outings even if this entailed restrictions on their social lives.

In addition, the parents of children with developmental difficulties worry about the future of their child, the level of his/her cognitive deficit and his/her ability to function independently as well as become accepted by the community and develop social networks. Bouma and Schweitzer (2006) have argued that the presence of a child with autism forces the family to face a variety of challenges, including 'varying degrees of bizarre stereotyped self-stimulation and unusual patterns of activity, language difficulty, social isolation, inappropriate emotional reaction to sensory experiences and deficiencies in social relationships, self-care and practical competence'(p.723). These challenges are likely to have implications for the formation of social networks.

Regarding the need for social networks, parents with compulsory education levels rated the importance of emotional support from other ASD parents higher than those with higher education. This finding demonstrates that parents with higher education levels are likely to have already developed social support networks.

Bebko et al. (1987) argued in their research that communication dysfunctions, restricted cognitive abilities and problems forming social relationships were the symptoms of autism that caused intense social problems to parents of school-age children. Phetrasuwan and Miles (2009) also found that handling the demanding behaviours and emotional outbursts of children as well as issues of discipline and behavioural management in public places were the sources of parental stress. Children with ASD's emotional reactions, expressions of fear or nervousness, verbal communication and interaction with others also increased parental stress levels. This resonates with the findings of this study since more than half the participants claimed

that their children demonstrated poor language communication and social interaction skills, affecting the whole family's social interactions.

Gray and Holden (1992) in their study of the psychological and social well-being of the parents of children with ASD included the amount of social support they received as one of the most important factors determining the appearance or not of parental depression, anxiety and anger.

Heaman (1995) suggested that the way parents of children with developmental difficulties chose to face the difficulties of the situation relates to their educational level and the age. Heaman (1995) suggested that mothers preferred strategies that included searching for social support and positive reevaluation of the situation, while fathers chose keeping their feelings inside and requiring less social support. The participants in this study clearly expressed their need to share their feelings and experiences with the immediate and extended family, seeking a social network.

Hastings et al. (2005) argued that the mothers and fathers of children with ASD reported higher stress levels compared to parents of children with other developmental disorders in terms of anxiety and depression, with social support and positive reinforcement being suggested by both parents as ways to address their feelings. The participants in this study claimed that they felt stress, anxiety and depression as a result of their child's condition. Parents also argued that the lack of formal support networks made them need more informal social support by interacting with other parents, sharing with peers having similar interests, as well as having an identity separate from being the parent of a child with ASD.

Furthermore, the participants in this study seemed to agree with the findings of Gray (2003) when he suggested that the way mothers and fathers of children with ASD tried to cope with the challenges of their child's condition was by being proactive and predicting some challenges that were bound to happen and designing a suitable response. They accepted problems would arise on a daily basis and thus focused on helping their children with the problems in the " here and now" (Gray, 2003) feeling it unnecessary to anticipate potential long term problems because of their unpredictable nature. It should be noted, however, that parents do not react in the same way to the challenges that arise since compared to fathers, mothers found a lot more difficulty in dealing with stereotypical behaviours and odd mannerism. Irrespective of education and gender, the parents of children with ASD experienced roughly similar challenges.

A further challenge that participants in this study had to face was the impact on the siblings of a child with ASD. Parents did not have enough time to develop a good quality relationship with them, pointing to the need for professional as well as informal help to deal effectively with their sibling's needs. Parents were also worried that the needs of children with ASD were likely to overwhelm the lives of their non-autistic children, something they found unfair. The findings of this research seem to be support the work of An et al. (2014) who suggested that the siblings of a child with ASD can be adversely influenced by the disability of their brother/sister due to reduced access to their parents and by the inability of their sibling/s to provide the kind of support and interaction that are common between non autistic siblings. Chan and Goh (2014) referred to the siblings of children with autism as the *forgotten siblings* due to the time and effort parents have to put in to provide for their child with ASD. An et al. (2004) also suggested that the siblings of children with ASD are likely to demonstrate poor peer relationships and feelings of loneliness as well as stress and anxiety.

The findings of this study seem to concur with Breitkreuz et al. (2014) that informal social support is very important in parents' attempts to deal with the challenges of raising a child with ASD. The link between reducing stress and social support is also clear from the findings of this study. For the parents, social support is a source of comfort that helps them to cope in the face of life's everyday challenges. Gouin et al. (2016), referring to Bronfenbrenner's (1977) model pointed out that 'social and family relationships are embedded in larger social structures such as communities, institutions and cultures. These structures influence the development of the individual'. Specifically, parents of children with ASD, are also significantly influenced by their level of access to formal support services. The provision of formal support services that come from health, social and educational services and the extent to which it hinders or facilitates the interactions between parents and professionals is discussed next.

5.4 Parent-professional collaboration

Social support studies on children with ASD and their families is still patchy and insufficient. Ku Lang et al. (2011) pointed out that 'the recent decade saw considerable improvements in terms of social awareness, supporting social systems, research, knowledge sharing and practices, as a result of the massive collective effort of individuals (e.g. parents, educators, researchers, clinicians, welfare workers and

policymakers)' (p.493). At the same time, Lilley (2009) argued that mothers are the driving force behind pedagogical efforts aimed at the overall community. The findings in this study indicated that on the whole, parents worked together with SEN teachers, special educators, speech and language therapists and educational psychologists and social workers 'seeing children with ASD as they are, and giving the support they need to improve their lives' (Ku Lang et al., 2011, p.493).

The Warnock Report (1978) and the Education Reform Act (1988) claim that addressing effectively the needs of people with developmental disorders depends upon the full participation of their parents in the process. The relationship between them and the health and education professionals is crucial to the development of the child. In order to support professionals' work, parents need information and clear guidance, while it is impossible for the professionals to meet the needs of parents and children without the parents' precious knowledge about their child. The participants in this study acknowledged that multi-disciplinary investigations are necessary if the needs of children with ASD are to be met effectively and efficiently. Kimpton, (1990) suggested that the diagnosis of any disorder is a very difficult time for parents as well as health professionals. Parents have the right to know what specialists think about their child. Clear explanations need to be given in order for parents to understand the seriousness and the gravity of the problem. Mumford, (1997) also suggested that the quality of the communication channels defines the quality of the initial and future interaction between parents and professionals. Renty and Royers (2006) highlighted the importance of the quality and content of the information given at the disclosure interview, because it is the starting point and the basin upon which the family can understand how to effectively help their child.

The participants' responses in this study seemed to support Mumford's (1997) claims since they reacted negatively to some professionals who did not help them enough to come to terms with their child's condition. The parents claimed that the professionals did not explain their child's condition clearly enough and did not offer advice about how to respond to this new reality in their lives. There were no gender differences evident with regard to their views on the support they received around children's ASD diagnosis; mothers and fathers reported similar views on their experiences regarding their children's diagnosis. However, a moderate gender difference was found regarding the information parents received about ASD. Fathers were more likely to agree with the amount of information given concerning the ASD

profile and needs than were mothers. Furthermore, fathers were more positive about their interactions with the professionals during their child's diagnosis for helping them deal with fears for their child's future, showing respect and being discrete, answering their questions honestly and offering their services continuously. Moreover, there were no differences in the ratings of parents-professional interactions and parental educational levels. However, a moderate statistical difference was found regarding the information provided about the appropriate educational provision by a special or mainstream school. That is, those parents with a compulsory education level rated the importance of this information more highly than those with a higher education qualification.

Mumford (1997) has argued that the expectations that parents have from professionals are directly linked to the way parents respond to the diagnosis of their child as well as the expectations they have for their child. Elston and Waine (1997) also argued that understanding how parents react to their child's diagnosis, while recognizing and respecting parents beliefs and expectations, can be regarded as a prerequisite for developing a working relationship between parents and professionals. Elston and Waine (1997) suggested that parents need time to balance internal contradictory feelings and external demands. The participants in this study found it very hard to accept the diagnosis of their child while at the same time, they felt rushed and thus divided between hope and despair, pride and shame about their child, normality and disability acceptance (Solomon and Chung, 2012).

Moreover, Redmond and Richardson (2003) argued that mothers are willing to care for their children but in order to do this effectively, they need the support of reliable, flexible and responsive services. The data presented in this study indicates that in addition to the difficulties of the day to day care of ASD children, much of the stress experienced by parents is related to the service responses offered to them, which they feel is inadequate, hard to access and not well coordinated. Renty and Royers (2006) argued that the support of professionals can be significant for helping parents become effective problem solvers, which can relieve them from the demands of the day to day care of a child with ASD and help them developing links with other families as well as services.

The participants in this study although acknowledging the importance of parent-professional cooperation, found the services to be fragmented and complex, resulting in

confusion about services provision. This was significantly problematic, with services often detracting rather than enabling them as careers.

Families of children with a disability who had not received useful support were found to tune to the needs of the ASD child (Florian and Krulik 1991; Sloper and Turner, 1992). Nevertheless, most parents considered help and support from professionals to be very important (Taanila et al., 2002). However, they seemed to regard the support they received as unsatisfactory and as a result, they continue to experience a range of negative emotions. These feelings developed and changed as time passed, but returned at critical moments. That is perhaps the reason why Estrella (2013) has argued that the psychological support of parents can be considered as a prerequisite for building a stable supportive family environment for the ASD child. Assessing the needs of the family of the child with autism is indispensable and inseparable from therapeutic intervention, but it only makes sense if it is accompanied by the information, support and counseling needed by the family of a child with a chronic disorder. Estrella (2013) claimed listening, educating, supporting and offering structure and normalization to parents of children with autism are essential.

Moodie-Deyer et al. (2014) suggested Andersen's theoretical framework is useful for exploring service utilization and access to medical care. This framework suggested that 'enabling components' of a population at risk serve as individual determinants of service utilization. Enabling components are described as the 'means individuals have available to them for the use of services' (Aday and Andersen, 1974, p. 213). Within this framework, enabling components include the attributes of the community (i.e., where a person lives, the availability of services, personnel in the community) and characteristics of people and/or their families (i.e. attitudes, perceptions, income, social support, etc.). Both types of components influence the probability of service use and satisfaction. Understanding individual characteristics and perspectives (rather than the system at large) is central, especially given individual variation relating to access to care (Moodie-Deyer et al., 2014, p.346). With this in mind, the participants in this study were very clear about their children's needs as well as the lack of services and resources.

Renty and Royers (2006) argued for the importance of evaluating the services for people with ASD to demonstrate any shortcomings regarding early identification, in particular. They found that 'although the symptoms are recognized by parents in early infancy, the average age of the diagnosis has been reported as ranging from 3, 5 to 6

years.' (p.123). Renty and Royers (2006) claimed that the way professionals tended to respond to parents' initial concerns was either inappropriate reassurance or gave the impression that parents were over-anxious. Consistently, the participants in this study struggled to make the professionals listen to their worries about their child. The parents felt or knew that something was not right with their child very early on, but they had to wait many months or years before getting a referral screening, or a diagnosis. The delay in diagnosis is of concern as parents recognized the importance of early intervention for improving the outcomes for their children.

Furthermore, open and flexible communication between parents and providers was described as an important characteristic of the positive experiences of accessing and receiving services. Many parents claimed that service providers didn't communicate with each other, creating barriers to effective service delivery. These views concur with Sloper's (1999) findings that 'fragmentation of support and lack of any overall view of the family needs are exacerbated by the lack of a single point of contact and coordination for families. Thus provision may be service rather than needs led' (p.90).

In the same line of argument, parents claimed that they felt abandoned by the professionals when receiving the diagnosis in that they were not given all the information they needed, especially information relating to access to financial resources. Some parents claimed that they had to be really determined in order to obtain a diagnosis or get a referral for the services they needed. This echoes the views of Dunst, Trivette and Deal (1994) who claimed that 'it matters as much how professionals assist families in mobilizing resources as it does which supports are mobilized' (p.ii). The features of effective help have been identified - among others - by Sloper (1999) as involving relationship building, communication honesty and clarity, and understanding families' own concerns. However, Estrella (2013) raised a note of caution, arguing that parents may not be so forthcoming about their needs or may appear to be able to cope with the information or the situation as a whole, when in reality, they are not able to.

Furthermore Wang and Brown (2009) in defining the concept of *quality of life* suggested this is based on meeting your individual needs, having choices in your life and being in control of it. Living a life of quality offers the opportunity to live life to the full in all areas of environments. Sloper (1999) also argued that parents have needs not met by the support services and their sense of having no control over their lives has been shown to be an important factor for the well-being of families. Parents experience a sense of control 'when they are in control of events and can obtain appropriate help

for their family and their child but parents often report problems with support services' (Sloper, 1999, p.89). The parents in this study echoed these views since they claimed state support was inadequate or professionals seemed indifferent, leading to feelings of confusion and the erosion of their sense of control.

James (2005) argued that the legislation, policy and strategies all favour multi-disciplinary work. This means that services and professionals should work together in ways that complement each other and enhance their roles and so maximize their capabilities. Wang and Brown (2009) claimed that family dynamics strongly influence the choices made. The role of the professional is to help family members understand their motivations and realize the extent to which the person with a disability influences the family's choices as well as that of the individual.

Renty and Royers (2006) pointed how important it is to find a common language to refer to both professional support and the needs of a family. The first step in offering the best possible professional care to the child with a disability is evaluating the experiences of service users and exploring what they need. Although the literature on this issue seems to clearly indicate the need for collaboration between parents and professionals, the parents in this study mentioned that ignorance on both sides can make the attempt to work together harder. At the same time, the professionals in this study acknowledged that they had received limited training themselves, specifically concerning autism which made collaboration with parents as well as inter professional collaboration difficult.

Peeters (2000) argued that training and seeing the world through the eyes of disabled people are key factors in maintaining good services. The basic elements that training about autism should cover include: 'understanding autism, assessing the afflicted person, adapting the environment to counter his handicaps, and using educational strategies appropriate to dealing with autism' (p.48). The professionals who participated in this study acknowledged that thirty or even thirty to sixty hours of autism specific training is not enough and that they needed a multi-disciplinary context to be more effective in their duties. They seemed to be in favour of Hartas' view collaboration as 'a dynamic system for educational efforts which endorses collegial interdependent and co-equal styles of interaction between at least two partners. These partners are working together to achieve common goals in learning and decision making processes that can be influenced by personal ideological and organizational factors' (Hartas, 2004, p.34). The professionals in this study seemed to favour a holistic

approach to each individual case presented through an individual education plan. The fact that an increasing number of children is allocated to professionals, coupled with the lack of or limited autism specific training they receive and the limited resources at their disposal contribute to the difficulties in achieving co-operation.

"*Most of us have attended some seminars. This does not mean that we have acquired specialized knowledge. You can't be responsible for a child in the autistic spectrum, from seminars alone. That is a crime. We have to have fulfilled a training programme, a serious post-training course, not only seminars. Some teachers have only attended seminars and some others do far more bad than good*" *(Professional 29).*

5.5 Factors that support or hinder collaboration

The care and education professionals in this study seemed to agree that collaboration is key to developing effective provision for children with ASD. At the same time, the professionals agreed that the information and communication flow between professionals is very difficult. They also suggested that due to the fragmentation of the services involved in helping children with ASD, cooperation between professionals and the coordination of services is difficult since professionals remain within their own professional boundaries. Bower-Russa et al. (2015) argued that 'while "what" is needed to work with [professionals] seems somewhat straightforward, the issue of "how" successful collaboration happens is more complicated.' (p.99) But Kelchtermans (2006) considered that 'collaboration and collegiality that only address the 'how to' question seem to contribute more to the status quo than to change or improvement' (p.228) arguing that 'a proper evaluation of collaboration and collegiality, thus, cannot but treat them as organisationally embedded phenomena that can take different forms and therefore can have different values' (p.225). For that reason since SEN schools as well as the K.E.D.D.Y. (Centersfor Differential Diagnosis and Support of Special Educational Needs) are distinct organizations with different agendas that offer education and care for children with ASD, the professionals were asked to determine ways in which collaboration could be meaningfully implemented. They understood collegiality and collaboration as an internal organizational process through which they would have the opportunity to share expertise and develop good relationships.

"*Interdisciplinarity is the central point. If there is no interdisciplinarity to find out what the other person has to say about a particular case etc., to listen to one another and to lead the team to a common decision, we have not achieved our goal. So, it is the central point of this collaboration, interdisciplinarity, consensus. Every professional has different angle and perspective on a situation that stems from his specialty, so when you marry them all, you have a more collective, more complete picture of the child and the family*" *(Professional 21).*

They also acknowledged that the current policies do not facilitate the development of such a culture since the Greek system is strongly centralized and leaves little room for autonomy and flexibility. Schucka et al. (2008) defined *professionalism* as 'the commonly understood effort of the individual to follow specific regulations, a defined way of communication, or a series of competencies deemed acceptable practice within a sector or specialty' (p.540). Although the majority of the professionals were in favour of collaboration perhaps the above definition including *acceptable practice within a sector or specialty* offers a reason why they felt the need to compromise as well as develop effective channels of communication in their attempts to cooperate effectively.

Fullan and Hargreaves (1992) argued that the goal is to develop a professionalism of interaction and cooperation involving decision-making on the terms and criteria of professional ethics, and a culture of support, solidarity and mutual trust. The participants in this study seemed to share Fullan and Hargreaves's views since they claimed that they were willing to make changes at a personal and professional level in order to support collaboration.

Kelchtermans (2006) pointed out that collaboration and collegiality do not happen in a vacuum, but in the particular context of a school. If we are to understand how collaboration and collegiality operate in action we need to approach them as meaningful interactions. Most professionals worked in SEN schools or KEDDY claimed their interactions with parents were excellent.

If we accept Kelchtermans' (2006) views, the question which arises is how do parents and professionals interpret and commit themselves to creating effective working relationships? The parents in this study were clear about what they expected from professionals and equally clear in suggesting that their needs were only partly met. The

parents indicated that they wanted to be involved in every aspect of the decisions made about their child and to feel respected and welcomed by professionals. The examination of the factors perceived to hinder the relationship between the professionals and parents of children with ASD revealed that most parents mentioned lack of resources, but parents were divided on whether parent –professional communication was a problem. A third of parents agreed that the limited accountability of professionals regarding their decision making and their time pressures were hindering factors. One in three parents reported lack of ASD specific knowledge was an obstructing factor in their relationships with professionals. Likewise, a third of parents felt that professionals were not adequately skilled and educated about ASD. One in five parents stated that their own (parents) limited time and one in four their lack of confidence in dealing with professionals were obstacles. However, almost a quarter saw lack of knowledge and understanding about ASD, as hindering factors and more than half of parents reported that their involvement in their child's therapy and the exchange of information with educational professionals were priorities for them. Furthermore, the need for parents to be trained in remedial programs was not met for a third of parents. More than half of parents stressed their need for feedback from professionals and to be well-informed about decisions regarding the treatment and education interventions for their child were partly met. Finally, less than half of parents stated that a welcoming atmosphere and cooperation with their child's special teacher were present. Although differences were not significant, fathers rated the provision of a welcoming atmosphere, involvement in the education plans and having their opinions and decisions valued with regard to their child's treatment and educational interventionsslightly higher than mothers.By contrast, mothers rated suggestions and feedback from the professionals, the exchange of information, their involvement in their child's treatments and therapies ,cooperation with the special teacher and the opportunities for parent training in remedial programmes more highly.

The participants in this study seemed to agree with Carpenter et al.'s (2001) claim that parents should not be treated either as recipients of information or as assistants to the professionals but as collaborators of equal value who interact with professionals within a context of mutual respect and dialogue at all stages of their child's treatment. A prerequisite for the success of collaboration between parents and professionals is, according to Peeters (2000), the training of parents. While Peeters (2000) wanted parents to be educated about autism, most importantly 'training in which professionals

and parents learn to collaborate is really the kind of training that is most needed' (p.53). The findings of this study indicate that this kind of training is difficult to achieve due to policy and practical constraints and lack of resources.

King et al. (2006) also argued that a strong peer network alongside high quality accessible information could be the key to family well-being and emotional resilience. The parents who participated in this study discussed the importance of advocacy, self-education, and empowerment to fill the gaps in unmet needs. At times, these methods could involve reaching out to other parents of children with ASD, perhaps through a self-help group. Gibson et al. (2017) point out that information seeking can be a coping mechanism for parents to help manage stress and, at the same time, help them make connections with other parents and communities of support. In this context, information seeking is important because it brings to the foreground the gaps between the information needed and what is available and accessible. As services and interventions evolve, the parents and carers of children with ASD face new challenges and experience different needs in terms of medical education and social information.

Moreover, lack of quality control, lack of trust, and the reduced applicability of general information to specific circumstances were cited as reasons in Gibson et al.'s (2017) research whereby some parents of children with autism chose to avoid using the internet as their information source of preference regarding autism. Parents in general were ambivalent about the internet and wavered between appreciation and distrust (pp. 2199-2200). Perhaps some parents in this study were ambivalent about the use of the internet for research purposes; most claimed they used the internet in order to connect with other parents, share their stories, find information, and normalize their experiences, although some also argued that in some cases, experiences of self-education through the internet were difficult and unproductive.

The findings about the difficulties that the parents in this study experienced in accessing the appropriate services and getting financial support seem to support Moodie-Dyer et al. (2014)'s claimed that insights from parents offer knowledge about what is working (and what is not) in terms of services and access. The participants also seemed to concur with Little (2003) in their claim of limited accessibility to ASD services. Finally, Moodie-Dyer et al. (2014) pointed out that offering individuals with ASD an intervention tailor-made to their unique needs is a significant challenge for the service delivery system, especially in difficult economic times. This is especially true for austerity- stricken Greece where the challenge to find publicly funded services is

becoming even greater. The final section of the discussion focuses on the Greek policy context and the extent to which the current ASD service delivery system meets the needs of the families of children diagnosed with ASD.

5.6 SEN policy within austerity

Theodoridou and Koutsoklenis (2013) argued that special education is part of the public educational system which is compulsory and free for all. This means that the government has to offer all that is necessary for ASD children in terms of programmes and resources as well as the diagnostic and assessment services. As Syriopoulou-Delli et al. (2012) pointed out 'in Greece, the idea of "*one school for all*" was introduced during the last decade (Greek Government Gazette, 2000) meaning that it needs time to evolve. Before the implementation of this legislation, children with ASD had access only to special schools for the mentally retarded. As a result, in some of these latter cases, parents would prefer to keep their children at home, or asylums, or youth institutions. Hence, these children were deprived of mainstream education' (p.755). Perhaps this explains why parents and professionals in this study wanted children with ASD not to be educated with children with different educational needs.

"*My child went to a special needs school and I tried hard to integrate him into a mainstream school, having a private tutor at home, to help him with the curriculum. When I wanted to move my child from the special to a mainstream school, the KEDDY report rejected my wishes with the excuse that the mainstream school was highly inappropriate for my child. I hoped that a mainstream school would give my child a better chance of fitting into society as he would learn social norms and what is and isn't acceptable, helping him to integrate into society. I would like his life to be pretty much as normal as possible. A special needs school is not able to develop my child's social skills in order to go out into society."(Parent F)*

The implementation of inclusive education in Greece, according to Avramidis and Kalyva (2007), faced a number of obstacles. From 1985 until the enactment of Law 2817/2000, inclusive education was implemented in " special classes" within a small number of primary schools in every county. The rationale behind 'special classes' was to facilitate the integration of pupils with a wide range of learning difficulties. The term

learning difficulties refers to problems with a varying degree of severity in language literacy or other learning difficulties. Up to eight students were included in each class with different learning difficulties in both nature and degree. On rare occasions, pupils with significant disabilities were also placed there with their parents' consent. Perhaps this is part of the reason why the participants in this study clearly suggested that although a lot of work needs to be done, some steps in the right direction have already been taken.

Avramidis and Kalyva (2007) pointed out that Law 2817/2000 enacted the 'design and development of individualized educational plans for children with SEN which should be accommodated within the general curriculum with the support of properly trained educational staff. It is for the first time specified that pupils with SEN should be educated for the most part in the mainstream classroom where they belong. Attendance in the integration unit is in turn limited to a few hours per week and no more than ten' (p.4). Syriopoulou-Delli et al. (2012) also claimed that since 2008, when the current special education law 3699/2008 was enacted, Greek students have two options: 'they can either attend a mainstream school class receiving additional support from the classroom or special education teacher or they can attend a special integration class within mainstream or vocational schools' (pp.755-756). The findings in this study clearly suggest that the professionals regard as part of their role, the creation of an IEP for their students. At the same time, mothers rated the importance of access to an IEP higher than fathers, while parents with a higher education level tended to rate having a school programme based on an ASD curriculum higher than parents with a basic compulsory education. Finally, all the parents included in this research sample wanted their children to be part of the mainstream school with parallel support in place.

Zoniou-Sideri et al. (2005) questioned the effectiveness of *special classes* which as she claimed were renamed *inclusive classes* without any changes made to their structure and operation. The model of special classes consisted of an add-on policy that does not affect the overall structure of the schools and does not require schools to change their practices. Vlachou (2006) in the same line of argument, suggested that the Greek inclusive class 'is much closer to the US resource or pull-out programmes, or to what the British describe as part-time withdrawal in a learning support base' (p.42). Maybe this is one of the reasons why the participants in this study did not support integration/inclusion classes as a concept. They also acknowledged that inter-collaboration as it stands, remains limited. The study findings indicate that the

participants might prefer the concept of *cross-fertilization* 'where efforts are made to encourage services to share and exchange skills and work across professional boundaries in ways that may readdress or redraw the boundaries themselves' (Hartas, 2004, p.35). The findings indicate that the professionals regarded every case as unique and their efforts were focused upon improving the circumstances of an ASD child and his/her family's by adapting to the difficulties s/he presents. This involves constantly assessing the situation, adapting the environment and on the basis of the assessment made, creating an IEP.

Moreover, all the parents wanted their children to attend general education and receive additional support within a mainstream school. This, according to Stampoltzis et al. (2012), may be due to the implementation of the 3699/2008 law, which 'gives the parents the opportunity to choose between special and mainstream education for their child' (p.1302). An additional reason that might have led the parents to support mainstream education could be their level of education. As most parents were university graduates, they were able to access resources related to the benefits of mainstream education for children with ASD. However, Stampoltzis et al. (2012) claimed that the related research literature does not indicate any particular education setting as more effective for students with ASD. The type of school is only one aspect along with the teaching methods and the curriculum of an effective education programme.

Sudhinaraset et al. (2013) argued that 'early diagnosis is important because early intervention can result in optimal outcomes. Although the symptoms of ASD can be identified within one year of life and reliable identification by clinicians can be made by age 2, the average age of diagnosis for children with ASD is 3.1 years' (p.747). The findings of this research correspond to the delays in diagnosis reported by parents, who blamed lack of infrastructure and lack of communication between services as the main reason. The parents' response to this issue of diagnosis suggests the nature of the cooperation between parents and professionals bears similarities to the 'expert model' where parents expect all the answers to come from the professionals, resulting in incomplete understanding and low satisfaction. This approach can make parents become overly dependent on professionals from whom they expect all the answers while their ability to help their child is reduced (Papageorgiou, 2004, p.4).

Teodorovic et al. (2016) also argued that 'stakeholders harbored negative feelings about educational policy reforms on the way these reforms were undertaken. They felt that their expectations were not met, their voices were not heard and that they were

inadequately supported for the implementation of those changes' (p.348). Applying Teodorovic et al. (2016)'s argument to this study, the stakeholder parents expressed similar feeling in terms of their difficulties in communicating with the professionals as well as the state, in their attempts to advocate for the rights of their children. The professionals in this study went one step further and claimed that the 3699/2008 current special education law is relatively clearly articulated but there are problems in policy adoption and budgeting and policy implementation (Teodorovic et al., 2016). Policy adoption and budgeting refers, according to Teodorovic et al. (2016) 'to the stage where a policy is actually enacted and assigned a certain budget, while implementation has to do with putting it into practice' (p.348). Both the parents and professionals claimed that the fact that the Greek state is undergoing austerity measures makes the implementation of policy even more difficult due to scarce resources being thinly spread (Renty and Royers, 2006). The participants also claimed that austerity means the state is unable to satisfy the growing demand for publicly funded services (Moodie-Dyer, 2014). In practice, this has meant that the parents had received very little financial support from the state towards their children's needs, compromising the quality of support they could offer to their children. This came up in this research for all the parents. No gender or education differences were found regarding the association of austerity measures and services provision, suggesting that both mothers and fathers and parents across educational levels shared similar views concerning the impact of austerity on ASD services.

Furthermore, Liasidou (2011) argued that there is a lack of coherence in Government policies, difficulties in defining specific concepts and a lack of clarity in purpose. The parents and professionals in this study found many gaps in the implementation of the 3699/2008 law, although it was a significant, but by no means adequate, step forward. Teodorovic et al. (2016) suggested that getting an insight from the most direct implementers of a policy is really important because they - the professionals in this study –'are the ones that convey and adapt policies grapple with their deficiencies and witness their successes or failures first hand; they can paint a vivid description of policies first hand not as they were intended but as they delivered' (p.350). Similarly, parents, as receivers on policy with their children, can access their merits or otherwise. The participants in this study highlighted the need for allocating more human and material recourses. More personnel was regarded as necessary for the stability, continuity and progress of the children.

Marshall and Patterson (2002) argued that policies can have a disorientating effect on educations due to their inconsistency and political pressures. This view was reflected in the findings of this study in the sense that both parents and professionals highlighted the necessity for a common language of understanding and co-operation. This approach can be considered as necessary according to Kondopoulou 's (2009) argument that from 2000 onwards, changes have been attempted in the field of special education in accordance with the Salamanca declaration, highlighting the special educational needs of some children, the inclusion of all children within a common educational framework and the creation of supportive structures. As a result, the 'special classes' were abolished and instead inclusive structures in the form of integrated classes, parallel support or home schooling were developed.

Furthermore, according to the most recent 3699/2008-FEK 199/A΄/2.10.2008 (Greek Government Gazette) K.E.D.D.Y. is a diagnostic evaluative and supportive governmental body that investigates and ascertains the special educational needs of students with disability and special educational needs. K.E.D.D.Y. assesses students with needs exhibited before their 22nd birthday. The assessment is carried out by a five member interdisciplinary team consisting of a SEN teacher (preschool or primary or secondary education), a child psychologist or pediatrician specializing in child neurology or a neurologist, social worker, psychologist and a speech therapist. The aim of the interdisciplinary team is to produce a holistic understanding of the problems and needs of the children and their families. Each professional contributes by taking on a set of responsibilities and goals, which are defined in team meetings. This makes it possible decisions for every child to be made collegiately to produce an intervention framework. While the participants of this study agreed with the content of the law, they were very clear that there are significant problems in its implementation. They argued that because the professionals come from different backgrounds, it is difficult for them to make an agreed decision for the child. As a result, a lot of valuable time is lost. Weiss et al. (2016) argued that the affordability, accessibility and availability of services are directly linked to parents' sense of self efficacy.

Many parents clearly expressed their inability to afford and access appropriate services for their children. They claimed that K.E.D.D.Y. is the body responsible for 'the detection and identification of the type and degree of difficulties of people with special educational needs in all preschool and school age children' (Article 4 of the 3699/2008 Law). Coupled with the fact that the cost of services related to the care of

ASD individuals is very high and the funding they get in the form of an allowance is very limited, especially nowadays, parents felt disillusioned and made helpless by the whole process.

Most parents acknowledged the need for continuous parallel support for their children. Article 7 of the 3699/2008 clearly states that the parallel support of pupils with ASD is interrupted only as a result of a consultation with the relevant K.E.D.D.Y. as well as parents. Parallel support for autistic students can also be provided by a special assistant employed by the students' family. Parents in this study further suggested that the referrals made by K.E.D.D.Y. resulted in the interruption of parallel support for their children. Some of the parents felt that offering their children parallel support was their attempt to 'try to create adaptive environments for their children by constructing normalcy' (Griffith et al., 2012, p.245). At the same time, N.3879/2010 ΦΕΚ 163/τ.Α/21-10-2010 linked to parallel suggests that all the energy and guidance behind the educational process is defined as an effort to help the child become an active part of a larger whole through the assistance provided. Ultimately, the issue was, and will continue to be, not just about signing up a student with special educational needs in a mainstream school with the sole aim of promoting his/her social skills; learning goals are necessary for all children. They are simply differentiated on the basis of their capabilities. This is a challenge both at school organisation level and at the level of cooperation between professional specialists.

A further attempt in the same direction was the constant efforts made by parents applying at municipal level for funding for afternoon activities for children with ASD. Parents suggested that given the lack of state funding for creative activities, coupled with the lack of appropriate resources and the difficulty in finding information, made this process even more difficult. As a result, parents felt that it was up to them to turn to the private sector and act as service navigators. This situation resulted in some of the parents feeling exploited.

Furthermore, the professionals in this study acknowledged the need for further autism specific training. This would seem to be necessary since most of them worked at K.E.D.D.Y. and the 3699/2008 law clearly states that one of the responsibilities of those who work at K.E.D.D.Y. is the 'authorization and development of customized or group psycho-educational and teaching support programmes or ways of occupying the children creatively in collaboration with the classroom teachers and the Special Education Curriculum'. The responsibilities of those who work at K.E.D.D.Y. also

includes the implementation of scientific social and other support measures for people with disability and/or special educational needs at home, at K.E.D.D.Y. and at schools. Perhaps this is the reason why the professionals in this study acknowledged that the hourly training that they received may have only offered them technical responses to specific "needs" or "syndromes" (Avramides and Kalyva, 2007) which they regarded it as by no means enough to meet the needs of children and their families. The professional responses as well as parents' requests for trained professionals suggested to the researcher the option of reflexive training to enable the development of generic' teaching skills that allow professionals to modify their practice (Avramides and Kalyva, 2007). Avramides and Kalyva (2007) specifically suggest that such training should include topics such as 'differentiating the curriculum, assessing academic progress, managing behaviour, developing IEPs, and working collaboratively with colleagues' (p.386). The participants in this study considered assessing children's progress and developing IEPs as part of their duties.

Vlachou (2006) suggested that the Greek education system is firmly controlled by the State; in practice, this means that the Ministry of Education makes all the decisions regarding issues related to the curriculum, training, personnel allocation, and resources. The findings of this study are similar to Vlachou's (2006) in the sense that the participants suggested that the Ministries of Health and Education follow centralized approaches firmly controlled by the State. There are different directives given to the two Ministries by the State and a top-down approach is followed in both cases. This in turn influences the provision and quality of services.

Both parents and professionals claimed that health and education services are under-resourced and under-staffed. Teodorovic et al. (2016) referred to teachers, counselors and principals as "street bureaucrats" (p.350) in the sense that they are expected to collect all the information needed in order to support a child more effectively and efficiently. They are expected to gather and organize the child's records, participate in intra and inter professional meetings regarding the child and communicate all the information to the parents. Vlachou (2006) referred to the 'unwillingness of an inflexible system to negotiate process and outcomes and meet the diverse needs of its pupils' (p.41). Professionals in this study who had worked at K.E.D.D.Y. mostly as SEN teachers, claimed that bureaucracy influenced issues such as diagnosis and welfare allocation as well as the allocation of recourses such as substitute and parallel support teachers.

Vlachou (2004) discussed enabling conditions for the creation of inclusive schools and suggested that partnership with professionals and making effective use of the available resources to support learning as starting points for improvement in an inclusive context. Vlachou (2004) also argued that 'the significant dependent variables in education are located in the kinds of interest levels of thinking activities and problem solving skills that students engage in when they are not at school. In other words the real test of successful schooling is not what students do in school but what they do outside of it'(p.10). The findings of this study indicated that despite the top-down enforced policies, the professionals believed in collaboration as an opportunity to develop good relationships and share experiences. They also claimed that despite all the infra-structure deficiencies, which have intensified during the period of austerity, they continue to improvise in accordance with the children's needs in order to effectively implement the curriculum. Finally, parents and professionals agreed that it is equally important for parents and children to spend quality time after school. At the same time, they noted that very few options were publicly available for children with ASD and most of those could be found in the private sector.

Milshtein, et al. (2010) argued that parents who have reached resolution regarding their child's diagnosis, although they acknowledge the difficulties involved, manage to cope with the condition and move on in life looking at the present and future with hope. Parents, who accepted their child's condition, were positive and focused on quality relationships with their immediate and extended family to satisfy their emotional support needs. Brown et al. (2011) defined *perceived needs* as *unmet needs* from the help-seeker's perspective and argued that 'service use may affect the parent's perceptions of need. For instance, parents whose children receive what they judge to be adequate services will most likely perceive fewer unmet needs' (p.1293). The participants in this study mainly preferred intervention programmes such as ABA which is based upon the principles of Behaviourism and aims to teach basic learning skills building upon the existing knowledge that the child has acquired. With the help of the parents and by continuing at school, the aim of the programme is to help the autistic child develop more skills and capabilities. The participants in this study also acknowledged the importance of the TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) which is based on structured teaching (Peeters, 2000). In both cases, the participants indicated their perceived needs had only partially been met. Searing et al. (2015) argue that the 'caregivers' perception

of whether support is helpful or not appears to be more influential on the health and wellbeing outcomes of caregivers, than the amount or type of support received' (p.3694). As pointed out, the perceived needs of the participants in this study were only partially met. Such a statement directly questions the existing resources.

The findings indicated that parents were in favour of their children being part of mainstream education. The more inclusive education becomes part of the landscape, the more it will be necessary for state and education professionals to work together to evaluate the academic outcomes as well as the allocation of resources and personnel.

The findings also suggested that further autism-specific training is necessary. The professionals agreed that the state should help by offering long term training that goes beyond dealing with specific needs. State and professionals of all disciplines could work together and offer training based on the principles of psychology and education and support reflective critical thinking.

Furthermore, the findings of this study indicated that ways to increase parental satisfaction can include the following: most parents and professionals in this study seemed to agree that the state should also offer continuity of service for persons with autism and their families. Parents made clear the need for permanent staff working with their children. This would make it easier for the parents to accept their professional opinion since relationships would be based on trust and time. Continuity of service could help save money in the long by avoiding unnecessary expenditure in an already lengthy and costly process.

In the same line of argument, the state could work with professionals in informing parents about the services and provisions available for their children. Parents could also receive clear and carefully worded expert information about the nature of autism. Having a better understanding about what autism is could help parents become more effective in their involvement in their child's treatment. Finally, more funding should be allocated to limit the period of waiting between initial consultation and diagnosis, as lack of knowledge is in itself highly stressful.

This chapter has discussed social support networks, parents' emotional responses, parent-professional interactions and stigma. Particular attention was paid to policy formulation and implementation in Greece, especially during the period of austerity. If inclusion has to do with the kind of education parents want for their children, then it became clear from the findings that parents and professionals were aware of what needs to change in an austerity stricken country. Parents, professionals

and the State need to work together at an educational structural and organizational level to communicate and collaborate to provide good services for children with ASD so they can achieve their potential and live an independent life.

5.7 Strengths and Limitations

The strengths and limitations should be taken into account when interpreting the results of the study. A strength is the triangulation of different data sources as part of a mixed-methods design. Despite the fact that a large sample was used, because it was not randomly selected (it came from three special needs schools in Athens that specialize in autism) its representativeness is questionable and thus the generalizability of the findings. The qualitative and quantitative components of the study question whether the breadth of the factors that hinder inter-professional and parent–professional collaboration have been captured in full. The same applies to the challenges parents of children with ASD face, especially since every case is different.The mixed methods research approach used in this study was found to be effective at empowering stakeholders to give their view on what was necessary for improving practice and the quality of life of ASD families.

Another strength of this study is the richness of the data collected from documents, questionnaires and interviews, allowing comparisons between them. Another strength is that it provides evidence from parents and professionals of how raising a child with ASD is a complex and all-enveloping experience and how the complicated interactions between the different aspects reflect the ever-changing nature of the challenges of parenting a child with autism. This research gave the parents a voice to recount their experiences influenced by the encounters that they and their child had with wider society and with the professionals they meet along their journey. Increasing awareness around ASD is a crucial step towards the acceptance of their children with ASD and, this research has highlighted the impact that public lack of understanding had on these parents, particularly in the early stages when they were adapting to and learning to manage their child's ASD. It is envisaged that the findings as a whole and, in particular, those related to the positive aspects of parenting a child with ASD, could be a useful resource for the parents of other children with ASD and help make professionals more aware of the situation of parents trying to raise their ASD child. And the impact it has upon other areas of their lives. Above all, although there are

aspects of raising a child with ASD that are common across peoples' experiences, there are also many aspects that are unique to the individual child and their family, and it is important to raise awareness of this.

Furthermore, in this study participated both fathers and mothers of children with a diagnosis of an ASD, but there were only twenty-two fathers in the total seventy-four sample of parents who completed the questionnaire and only five of were interviewed. The findings from this study suggested that within some Greek families, there may be clearly defined gender roles. Having a more homogenous sample interviewing only fathers or mothers alone may have led to further findings. Whistle the current findings represent the experiences of these particular parents, they may not be representative of all or even most parents.

Another limitation was that this research took place in the Attica urban region. The findings might be different in a rural area. Furthermore, all the parents who participated in the research were Greek. Parents of different ethnicity or socioeconomic status may have different perspectives than the parents in this study. Western and Asian cultures can vary considerably with regards to family, community, and education and the results of this study should be applied to other countries with caution. Challenges change within the life cycle and the challenges of adult life leave much to investigate. Specifically, the transition to adult life and employment is an area that is ripe for investigation and further study. Parenting does not stop once a child with ASD reaches adulthood and the experiences of parents of adults with ASD could be enlightening and help to guide effective policy development to best meet the needs of individuals with ASD and their families.

The absence of an Educational Counsellor's perspective is a shortcoming of this study. The Educational Counsellor's perspective would benefit further study to add to the pool of knowledge.

Bearing all the above in mind, there is always the hope that people's attitude to ASD will change and more programmes will be created to provide more help for children with ASD in the Greek educational context, in order to give them the chance to have the same opportunities in their educational process and in their future life as others.

5.8 Future Research Directions

All the research to date suggests further studies should be undertaken. The key areas in which the findings of this study could be built upon and taken forward are: through undertaking a similar study with a different population (e.g. adults with ASD and their parents, schools administrators); through undertaking research to identify the service providers' perspectives, researching the impact of austerity on disability support or the impact of short breaks on family stress; research the coping strategies identified in this study to see how robust they are.

Future research investigating the needs and well-being of parents raising a child with ASD could expand the research design by implementing longitudinal studies that incorporate evaluation of the quality of the services provided. Longitudinal studies could also help demonstrate how the needs of parents of children with ASD change over time, from the time of diagnosis and following the development of their child over time. This could also contribute to a better understanding of autism as a concept, what it is and what it entails.Furthermore, public and parental attitudes towards disability, changes in educational legislation in Greece must be taken into consideration for future study. It would be interesting to explore the potential of support interventions for siblings. For example, internet support forums may be one possible area and have been shown to be beneficial for other groups, such as children with special needs siblings.

Another interesting avenue for further studies could be to investigate how autism relates to stress and depression and whether it mediates these variables and other aspects of parental well-being. Such findings could lead to the development of future interventions directed at increasing the well-being of parents of children with ASD. Interventions aiming to support parental feelings may be optimized when combined with high quality evidence-based services. The findings of this study indicated that achieving this goal requires a well-rounded approach to meet the needs of each individual. Such programmes are based on identifying specific issues that are detrimental to parents and children respectively. Future intervention strategies should strive to concurrently provide parent and child focused training and treatment.

Given the limited research in the Greek educational context regarding the parents and professionals' perceptions of the challenges of supporting children with ASD in the straitened times of austerity, it is felt that further research needs to be conducted that will establish the most beneficial way of supporting the parents of these children (e.g. establishing a governmental body offering guidance, counselling, practical and

emotional support services - broadening the role of K.E.D.D.Y.) putting them in touch with other parents of children with ASD and helping them to understand their child's needs.This study offered additional insights into what is valued by caregivers. The participants in this study wished the best possible outcomes for their children in terms of their quality of life. This means being safe and well, being engaged in meaningful activities and having social contact. In order to achieve this outcome parents and professionals suggested that further state funding is necessary in the form of focused incentives. An area for further studies could be the environmental support that should be offered to children with developmental difficulties given that they have difficulties in understanding and interpreting the requirements of their environment.

Finding ways to achieve visual facilitation could be another area of exploration children with developmental difficulties understand more easily what they can see. Furthermore, creating an environment that is as organized and as predictable as possible can help children feel more independent.

The participants in this study argued that some steps have been made in terms of understanding and implementing inclusion, but still a lot of work needs to be done. Children with ASD need a specially structured environment that will allow them to learn skills and feel the satisfaction of creating something on their own. The purpose behind inclusion is not to offer the same opportunities but equal opportunities to all children. This occurs by taking account of the individual needs of every student (Paraskevopoulos 2008). In practice, this means that research should inform practice in the sense that the more we understand what autism is and entails the more will be able to offer children less restrictive environments within which they can develop their potential. It is further hoped that this study has identified areas for future research which will contribute to the international arena in the understanding and management of autism.

Further – and longer that a few hours - autism specific training is a necessary base for effective inter - professional collaboration. Further research into autism is necessary as well as the creation of training centers for professionals who specialize in autism. This is an important issue raised by necessity, given that the number of children with ASD is on the increase (Gena 2006). Creating training centers should be part of a long term government plan that acknowledges the need to offer more than on the job or in service training on autism.

Finally, the state educational system should offer a variety of choices in terms of educational frameworks that better facilitate the needs of children. Professionals should work together in order to find a balance between intrusiveness and effectiveness regarding their approach. If one of the aims behind inter-professional collaboration is to maximize the use of resources and support positive developmental outcomes, reciprocal consultation (Hartas, 2014) might be the way forward despite the difficulties between families or organizations, and this is worth testing out and in practice would involve cooperation between the Ministries of Health, Education, and Employment and Social Solidarity respectively. This can be achieved through operating Centers of Information where all the available services as well as information related to the legal rights of a person with autism would be on offer to families.

Collaboration between the structures that offer autism related support (i.e. respite centers, private centers, KEDDY) might also be another approach. Further research needs to be conducted in order to understand the best collaborative processes and practices, as well as the role of protocol and emergent practices in the achievement of collaborative aims. The departments of Health and Education should pay close attention to the developments of new therapeutic approaches and educational programmes respectively outside Greece. Joint research programmes as well as the creation of vocational training programmes for professionals that specialize in autism might be another area for future research. This study has suggested that under certain circumstances, the process of inclusion of children with ASD in mainstream schooling could be successful. This requires cooperation between not only the parents but also the wider community. At the same time, Krantz (1998) reminded us that it is not the space in which the children are studying that is important but rather the way and the conditions in which they do so.

CHAPTER 6: Conclusion and Implications

The findings of this research show that being the parent of a child with ASD within a context of limited support, is characterised by many meaningful experiences, several of which are particularly significant. For example, the journey to get, and receive their child's diagnosis was identified as exceptionally important for these parents. The parents' experiences were influenced by the encounters that they and their child had with wider society and with the professionals they meet along their journey. Being a parent caring for a child with ASD in the context of reduced public services and social conservatism with regards difference and disability whereby children and their families are stigmatized is a traumatic experience. The professionals worked hard but were demoralized by cuts in services and the limited training and professional development offered. There were wider issues - institutionalized discrimination against children with ASD, the state not providing support to meet their needs and the onus falling on parents to bridge any gaps. Their quality of life was impacted by the level of stability and continuity of the formal and informal services. K.E.D.D.Y. Centres did not fulfill the parents' expectations for better educational services for their children. The inclusion of these children is difficult to be implemented in practice due to the lack of mainstream structures.

This study could contribute to an increasing awareness of the challenges that parents and professionals face in responding to the needs of ASD children in Greece. The findings concerning the discrimination and stigma experienced by individuals with autism and their families constitute an area where the whole of society requires education and should be part of the general curriculum. What better way than through inclusion, so the *normal* lose their fear of the *different.* Given the strong support for the social aspect of inclusion from the data, wider knowledge of autism in the general public could help reduce the stress of ASD families. Future research could attempt to access the attitude of the general public to ASD and its misconceptions, within the concept that ASD is a social concern and thus, from a holistic perspective, the views of the general public contribute to both the problem and its solution. The views of parents and professionals who deal with ASD children expressed in this study could offer suggestions about improving the everyday life of children with ASD, but as pointed out above, these views are only part of the picture. More importantly, this study could lay the basis for practical ideas in terms of effective integration of autistic children into the

community, including through better general education, as suggested above. The results of this study highlighted the importance that parents of children with ASD attach to their children's happiness and well-being and to their cooperation with professionals, but community support would also reduce stress.

Finding a shared language of communication is necessary to better understand the emotional and behavioural needs that people with ASD experience, especially since this is something that highly influences their families and communities, who also need to be access information about ASD children in inclusive schools and value them as individuals, with a social role to play. This study has also highlighted the need for a good match between parental and professional priorities and focus. The results suggests that both the capabilities of the individual child and the social context appear to influence parental perceptions of the likelihood of their children achieving a better life in the future especially after they pass on. The importance of the attitude of wider society is also stressed.

This study also suggests that early interventions increase the likelihood of positive outcomes for children with ASD and they should target the social environment level to have lasting effects. Thus, efforts to improve and monitor outcomes should place emphasis on the quality of life and the participation of the parents of children with ASD in the decision making process.

The results of this study indicate that the parents of a child with ASD are in need of empowerment and emotional support, irrespective of their education level or financial resources. Counseling parents of children with ASD may be an area for further study and research, especially since it is indicated by the participants that their needs remain uncovered in this area. Parents of children with ASD face a reality in which they feel alone in their attempt to fight a series of dipoles such as hope and despair, perfection and disability, shame and pride. A family that raises a child with ASD needs guidance, support and counseling that is long term and on this understanding, emphasis must be placed on the positive aspects of every family and the process of strengthening the bond between the family members, and ultimately, the social context in which they live.

The findings revealed the need to establish boundaries between parents and professionals. If the process of cooperation between them is based upon clearly defined guidelines, it can help parents create a functional and positive climate within the family unit. Creating a positive climate can contribute to the development of a child with ASD

since it will help the quality of interaction and communication between parents and children. Furthermore it will also address the family dynamics and create a framework for dialogue between parents and professionals on intervention programs.

Moreover, the findings of this study also suggested that many of the parents that contact professionals lack information regarding the existence and operation of supportive services and programmes. Further research could focus on finding ways to inform parents about the nature of services their children need and are available and accessible to them. The parents and professionals in this study seem to be in favour of 'the partnership model' where every kind of formal informal or pedagogical support puts the child within the family at the center. In this long term process, parents and professionals can make different contributions of equal importance. The results of this study highlight that the child's deficiencies influence the immediate as well as the extended family and to a certain extent, the social community within which the family is called to actively partake.

On this understanding, parents need to be treated as partners who interact with professionals in a context of appreciation and respect at every stage of the process, from initial assessment to deciding upon the nature of the intervention. The aim remains the same: to create the best possible circumstances for the child to adapt effectively, as for any child. This, in everyday life, means that professionals from different fields such as SEN teachers, psychologists, social workers, speech and language therapists and children psychiatrics need to work together alongside parents in the best interest of the children.

The parents who participated in this study argued that they needed well organized and resourced services for their children. They also claimed that, for their children to achieve the best they can, they need to work with the same key worker for long periods in time to help children and professionals co-operate effectively and lessen the feelings of anxiety and stress that the parents of children with ASD constantly experience.

The professionals claimed that it is important for them that parents acknowledge their commitment to their child so that the quality of their role is not restricted. The professionals felt that parents need to understand the constraints under which they work: lack of staff, inadequate funding, and lack of time.

There are issues that need to be taken into consideration. Although the research was conducted in Greece and all the participants were residents of Athens, the place of

residence might have an influence upon the services available to ASD parents and their children. This study was conducted in Greece during austerity, which provides a particular cultural, social, and educational context that might not be directly comparable to that of other countries with similar sociopolitical structures. It also offered a lens through which attitudes towards disability and difference are viewed and the value of human life, especially when the resources are scarce. Attitudes of discrimination and stigmatizing difference can be addressed through education and government support through information dissemination – perhaps on a government website – as a start and would not be highly expensive.

This study highlighted the overall lack of appropriate therapeutic services in Greece that has intensified even further due to the lack of funding and resources. As a result, the time as well as the treatment that state doctors and other professionals allocate to all children with ASD are limited and it is up to the parents to find ways to meet their children's needs. In this context, social support and better understanding of difference by the general public can make a contribution.

The state also recognizes that although the functionality and skills of children with autism can develop through education and training, they cannot live independently. Instead they need constant supervision and care as well as simple work structures. It is also recognized that is the responsibility of the state to provide when the family is no longer there, to provide a humane and dignified life for these children.

At the same time, specialized centers are scare in Greece and schools that support SEN children do not accept the more serious cases. But even for the children that follow the mainstream school programme, parallel support and counseling are not always available. As a result, parents have to resort to private professionals and centers and are unsure about the capabilities of the professionals and the effectiveness of these centers. Being part of the mainstream school has been recognized in Greece as a legally protected right for children with developmental difficulties. The larger part of the responsibility for implementing inclusion lies with the education system, not the nature of the difficulties related to autism. New strategies need to be developed and programmes that have been proven effective in other countries could provide the basis of a model for Greece. This means that innovative ideas to be tried and tested should fall within the framework of the Greek legislation.

Approaching autism is neither simple nor easy, especially in a country where professionals need to work together by taking small, critical steps in strictly

personalized contexts. The first step after accepting a child's condition to start to look for a different and better future based on the premise that despite the differences of autistic children, every child is unique and all of them deserve to feel loved and accepted.

If parents and professionals, society and the state are to be successful in their role as careers of a child with ASD, they have to be dynamic to understand and meet the different needs of the children. Information from this study could also help guide the development of infrastructure for ASD individuals in domains that parents consider important. For instance, more educational, vocational and independent or supported living opportunities for their ASD children are clear priorities for parents. This study also highlights the need for teaching the appropriate skills and competences to children with ASD on the basis of IEPs as well as individual assessments. Examining the long term relationship between caregivers' expectations and children's outcomes using various methodologies could help enhance the collaboration between these stakeholders in intervention, adult support services and transition efforts.

There is a strong need for a comprehensive state-maintained support system in Greece that caters for parents' needs and expectations for their children with ASD. This system could consist of a variety of professionals (i.e. teachers, services providers, educators, financial advisors) that could meet the individual needs of families struggling to help their children with ASD, along with local community members.

One of the contributions of my study is the richness of data demonstrating the intensity and range of parental feelings. They had some very negative feelings but were full of hope for their children at the same time. Another contribution of my findings could be the identification of many obstacles parents have to face in order to deal with their children's needs. Even if parents have to fight against the odds for their children with ASD, this study has demonstrated it is possible to create more positive circumstances for their children.

Another strength of this study is its exploration of the role of disability/ASD services and provision for children with ASD under circumstances of austerity indicating the unmet needs of the families of these children that can help policy makers and service providers to develop resources and services that are responsive to these parents in austere times.

More appropriate sensitizing of parents and professionals will hopefully lead to better intervention programs, self-esteem and self-identity enhancing strategies and consequently, to a reconceptualization of ASD within the Greek context. According to

the findings, the Greek Educational system needs to provide adequate training opportunities for SEN professionals, facilitate co-operation with other professionals (e.g. educational psychologists, speech therapists, children's psychiatrists) who could work together with SEN teachers in devising intervention programmes, and provide better public information to reduce prejudice.The importance of professionals 'working together' effectively with schools and families to promote positive outcomes for children with SEN has long been a focus of government guidance and legislation in other countries (e.g. Children's Act, 2004, DfE, 2013), which have already created many of the improvements which Greece is seeking and could offer a good model.

It is hoped that this study can contribute in some measure to the emerging understanding of autism in Greece, and that the implementation of some of the recommendations made here could increase the effectiveness of the recent efforts to cater for the needs of children with ASD and their families.

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Appendices

Appendix 1

1. TABLE - SAMPLING

State Schools for ASD Children	K.E.D.D.Y.	Area of Greece	Parents	Professionals
1st ASD Special School	A K.E.D.D.Y	Athens Attica	100	20 Special teachers
2st ASD Special School	B K.E.D.D.Y.	Athens Attica	100	20 Psychologists
3st ASD Special School	Peiraias K.E.D.D.Y.	Peiraias Attica		20 Speech and Language Therapists
				20 Social workers
				20 Special Educators
				10 Occupational Therapists
				10 Children's Psychiatrists

Appendix 2

Letter of Research Approval from Greece

HELLENIC REPUBLIC
MINISTRY OF EDUCATION AND RELIGIOUS AFFAIRS
GENERAL DIRECTORATE OF STUDIES FOR PRIMARY AND SECONDARY EDUCATION
DIRECTORATE OF SPECIAL EDUCATION
DEPARTMENT A
Post. Address: 37, Papandreou Str. – GR 151 23
City: Marousi
Website: http: // www. minedu.gov.gr
Email: t08dea3@minedu.gov.gr
Information: X. Touroukis
Phone: 210 3442928-29
Fax: 210 34423193

Marousi, 09-01-2015
Ref. No. 2712 / D3

TO: 1) VERONI EIRINI, 52, GRAMMOU STREET, AGIOI ANARGYROI GR13561, ATHENS.
2) REGIONAL DIRECTORATE OF PRIMARY AND SECONDARY EDUCATION OF ATTICA
3) DIRECTORATES OF PRIMARY EDUCATION: ATHENS, PIRAEUS, EASTERN ATTICA
4) KEDDY: A ATHENS, B ATHENS, PIRAEUS (THROUGH THE REGIONAL DIRECTORATE OF ATTICA).
5) SPECIAL PRIMARY SCHOOL FOR AUTISTIC STUDENTS IN AEGALEO, SPECIAL PRIMARY SCHOOL FOR AUTISTIC STUDENTS IN PIRAEUS, SPECIAL PRIMARY SCHOOL IN NEA MAKRI (THROUGH THE CORRESPONDING DIRECTORATES OF EDUCATION).

Re: Research Approval.

Please be advised that according to the Proposal (Ref. no 15 056/12.24.2014) of the Head of Research, Design and Application Office A of the Institute of Educational Policy (hereinafter referred to as IEP)the Board of IEP hereby approves (Act No. 74 / 15-12-2014 of the Board of IEP), the research by Mrs Veroni Eirini as part of her obligations towards obtaining a Ph.D. degree from the University of Warwick, entitled "An assessment of parents' needs on how to raise a child with autism spectrum disorders."

The purpose of this research is to investigate the practices adopted and the challenges faced by parents of pupils with autism in the upbringing and education of

their children. The research feasibility of this issue is based on the lack of relevant research in our country and on the contribution that this research will make to improve the provision of educational and other services to parents of children with autism, as well as to the children themselves.

This study has a clear targeting and is distinguished by the extensive references to relevant research conducted and found in the international bibliography.

The research methodology:

During the process of collecting research data the researcher will ask the parents of students studying in the specific schools and the teachers of the sample to complete a questionnaire directly compatible with the object under study. In addition, semi-structured interviews with a subgroup of parents and professionals from the above schools and institutions will be conducted by the researcher and individualised educational programs designed by the teachers for the pupils of the particular schools will be studied. All participants in the research will give their consent. All the relevant rules of research ethics will be respected, the anonymity of the members of the sample will be preserved and the sound records will be destroyed.

The collection of research data will begin in the current school year and will be completed in 2016. Special education professionals will participate outside their working hours.

The survey sample:

A survey sample of 100 parents of children with autism, as well as a sample of 100 professionals (psychologists, special education teachers, social workers, etc.) working in the field of special education will be used. The specific parents and professionals will be chosen from six similar structures: from three special primary schools attended by pupils with autism and from three Centres for Different Diagnosis, Diagnosis and Support of Special Educational Needs (KEDDY) based in the Athens area.

The Head of Special Education

Konstantinos Lolitsas

True certified copy of the original

ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ
ΥΠΟΥΡΓΕΙΟ ΠΑΙΔΕΙΑΣ ΚΑΙ ΘΡΗΣΚΕΥΜΑΤΩΝ

ΓΕΝΙΚΗ ΔΙΕΥΘΥΝΣΗ ΣΠΟΥΔΩΝ ΠΡΩΤΟΒΑΘΜΙΑΣ
& ΔΕΥΤΕΡΟΒΑΘΜΙΑΣ ΕΚΠΑΙΔΕΥΣΗΣ
ΔΙΕΥΘΥΝΣΗ ΕΙΔΙΚΗΣ ΑΓΩΓΗΣ
ΤΜΗΜΑ Α

Ταχ. Δ/νση: Α. Παπανδρέου 37
Τ.Κ. – Πόλη: 151 23 Μαρούσι
Ιστοσελίδα: http://www. minedu.gov.gr
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Πληροφορίες: Χ. Τουρούκης
Τηλέφωνο: 210 3442928-29
Fax: 210 34423193

Μαρούσι, 09-01-2015
Αρ. Πρωτ.2712 /Δ3

ΠΡΟΣ: **1) ΒΕΡΩΝΗ ΕΙΡΗΝΗ, ΓΡΑΜΜΟΥ 52, ΑΓΙΟΙ ΑΝΑΡΓΥΡΟΙ ΤΚ 13561, ΑΘΗΝΑ.**
2) ΠΕΡΙΦΕΡΕΙΑΚΗ ΔΙΕΥΘΥΝΣΗ ΠΡΩΤΟΒΑΘΜΙΑΣ ΚΑΙ ΔΕΥΤΕΡΟΒΑΘΜΙΑΣ ΕΚΠΑΙΔΕΥΣΗΣ ΑΤΤΙΚΗΣ
3) ΔΙΕΥΘΥΝΣΕΙΣ Α/ΘΜΙΑΣ ΕΚΠΑΙΔΕΥΣΗΣ : Γ ΑΘΗΝΑΣ, ΠΕΙΡΑΙΑ, ΑΝΑΤ ΑΤΤΙΚΗΣ.
4) ΚΕΔΔΥ: Α ΑΘΗΝΑΣ, Β ΑΘΗΝΑΣ, ΠΕΙΡΑΙΑ (ΜΕΣΩ ΠΕΡΙΦΕΡΕΙΑΚΗΣ ΔΙΕΥΘΥΝΣΗΣ ΑΤΤΙΚΗΣ).
5) ΕΙΔΙΚΟ ΔΗΜ ΣΧΟΛΕΙΟ ΑΥΤΙΣΤΙΚΩΝ ΑΙΓΑΛΕΩ, ΕΙΔΙΚΟ ΔΗΜ ΣΧΟΛΕΙΟ ΑΥΤΙΣΤΙΚΩΝ ΠΕΙΡΑΙΑ, ΕΙΔΙΚΟ ΔΗΜ ΣΧΟΛΕΙΟ ΠΑΜΜΑΚΑΡΙΣΤΟΥ(ΜΕΣΩ ΤΩΝ ΟΙΚΕΙΩΝ ΔΙΕΥΘΥΝΣΕΩΝ Α/ΘΜΙΑΣ ΕΚΠΑΙΔΕΥΣΗΣ) .

ΘΕΜΑ: **Έγκριση Διεξαγωγής Έρευνας.**

Σας γνωρίζουμε ότι σύμφωνα με την Εισήγηση (αρ.Πρωτ. 15056/24-12-2014) του Προϊσταμένου του Γραφείου Έρευνας, Σχεδιασμού και Εφαρμογών Α του Ι.Ε.Π., εγκρίνεται από το Δ.Σ. του Ι.Ε.Π.(Πράξη υπ. αρ. 74/15-12-2014 του Δ.Σ. του Ι.Ε.Π.), η διεξαγωγή έρευνας της κ Βερώνη Ειρήνης στο πλαίσιο των υποχρεώσεων της για την απόκτηση διδακτορικού τίτλου Σπουδών από το Πανεπιστήμιο του Warwick, με θέμα: «Μια εκτίμηση των αναγκών των γονέων σχετικά με το πώς να μεγαλώσουν ένα παιδί με διαταραχές του φάσματος του αυτισμού».

Σκοπός της έρευνας αυτής είναι η διερεύνηση, αφενός, των πρακτικών που υιοθετούν και αφετέρου των προκλήσεων που αντιμετωπίζουν οι γονείς μαθητών με αυτισμό ως προς την ανατροφή και την εκπαίδευση των παιδιών τους. Η ερευνητική σκοπιμότητα του συγκεκριμένου θέματος στηρίζεται στην έλλειψη σχετικών ερευνών στη χώρα μας και στη συμβολή που θα έχει η συγκεκριμένη έρευνα όσο αφορά τη βελτίωση των παρεχόμενων εκπαιδευτικών και λοιπών υπηρεσιών για τους γονείς παιδιών με αυτισμό αλλά για τα ίδια τα παιδιά.

Η συγκεκριμένη μελέτη έχει σαφή στόχευση και διακρίνεται για τις εκτενείς αναφορές σε συναφείς έρευνες που έχουν διενεργηθεί και απαντώνται στη διεθνή βιβλιογραφία.

Η μεθοδολογία της έρευνας:

Κατά τη διαδικασία συλλογής των ερευνητικών δεδομένων θα ζητηθεί από την ερευνήτρια να συμπληρώσουν οι γονείς των μαθητών που φοιτούν στα συγκεκριμένα σχολεία και οι εκπαιδευτικοί του δείγματος ερωτηματολόγιο άμεσα συμβατό με το προς μελέτη αντικείμενο. Επιπλέον θα διενεργηθούν από την ερευνήτρια ημι-δομημένες συνεντεύξεις με μια υποομάδα γονέων και επαγγελματιών των ανωτέρω σχολείων και πλαισίων και θα μελετηθούν τα εξατομικευμένα εκπαιδευτικά προγράμματα που έχουν σχεδιασθεί από τους εκπαιδευτικούς για τους μαθητές των συγκεκριμένων σχολείων. Θα διασφαλιστεί η συγκατάθεση όλων των συμμετασχόντων στην έρευνα. Θα τηρηθούν όλοι οι προβλεπόμενοι κανόνες της ερευνητικής δεοντολογίας, θα διαφυλαχτεί η ανωνυμία των μελών του δείγματος και θα καταστραφούν τα ηχητικά αρχεία.

Η συλλογή των δεδομένων έρευνας θα ξεκινήσει κατά την τρέχουσα σχολική χρονιά και θα ολοκληρωθεί το 2016. Η απασχόληση των επαγγελματιών ειδικής αγωγής θα γίνει εκτός ωρολογίου προγράμματος ή ωραρίου εργασίας.

Το δείγμα έρευνας:

Θα χρησιμοποιηθεί δείγμα έρευνας από 100 γονείς που έχουν παιδιά με αυτισμό, καθώς και δείγμα 100 επαγγελματιών (ψυχολόγων, εκπαιδευτικών ειδικής αγωγής, κοινωνικών λειτουργών κ.α) που εργάζονται στον χώρο της ειδικής αγωγής. Οι συγκεκριμένοι γονείς και επαγγελματίες θα επιλεγούν από έξι ανάλογες δομές: από τρία ειδικά δημοτικά σχολεία που φοιτούν μαθητές με αυτισμό και από 3 Κέντρα Διαφοροδιάγνωσης, Διάγνωσης και Υποστήριξης Ειδικών Εκπαιδευτικών αναγκών (ΚΕΔΔΥ) που εδράζουν στην περιοχή της Αθήνας.

Ο ΔΙΕΥΘΥΝΤΗΣ ΤΗΣ ΕΙΔΙΚΗΣ ΑΓΩΓΗΣ

ΚΩΝ/ΝΟΣ ΛΟΛΙΤΣΑΣ

Εσωτερική Διανομή:
1. Γραφείο Υφυπουργού
2. Δ/νση Σπουδών Π.Ε.
3. Δ/νση Ειδικής Αγωγής

Appendix 3

Letter to Parents and Professionals

I'm a teacher in Primary Education with many years of teaching experience in the area of state special education. During my duty in several services like the Centre for Differential Diagnosis, Diagnosis and Support (KE.D.D.Y.) and the School Units for Special Education (S.M.E.A.E.). I found from by experience that parents who have children with Pervasive Developmental Disorders find serious difficulties in dealing efficiently with their children's issues. So, I decided to analyze these difficulties in a scientific way. This decision prompted me to study at Warwick University where I started writing my thesis. Specifically, the aim of my research is, on the one hand, to investigate the problems that families in Attica confront trying to deal efficiently with their children who have the Autism Spectrum Disorder and, on the other hand, how they can develop a constructive collaboration between themselves and the professionals who deal with their children. I am convinced that this research will produce significant information about how to improve the services provided to parents with autistic children. I would like to ask for your contribution to my research, by completing the questionnaire attached, which is about parents whose children are within the Autistic Spectrum Disorders (ASD).

You have my assurance that all your answers will be kept confidential as the questionnaire is anonymous. The estimated time for completing the questionnaire is no more than fifteen minutes.

I would like to thank you in advance for taking part in my research.

Yours sincerely,

Eirini Veroni
PhD Researcher

Appendix 4

Consent Form

You are kindly requested to read the following sentences carefully and then tick the appropriate box in the form.

1. I confirm that I am aware of the aim of the present research

☐

2. I understand that my participation in this research is voluntary, and I have the right to withdraw at any time if I wish to do so.

☐

3. I understand that the information will be kept confidential and used strictly for the purpose of this research alone.

☐

4. I agree to take part in this research, by completing the questionnaire looking into the needs of families bringing up autistic children.

☐

5. I would like to receive the results of the current research via email.

☐

Parent's name: _____

Parent's signature: _____

Date: _____

Researcher's name: _____

Researcher's signature: _____

Date: _____

Appendix 5

QUESTIONNAIRE FOR PARENTS WITH CHILDREN WITH ASD

PARENT VIEWS ON ASD DIAGNOSIS AND SUPPORT

Personal Characteristics

1. **What is your relationship to the child who has an autism spectrum disorder?** ☐ Mother ☐ Father Other (please specify): _____

2. **What is your highest level of education completed?**

☐ Less than a high school diploma

☐ High school diploma

☐ College diploma

☐ University undergraduate degree

☐ University graduate or professional degree

3. **What is your marital status?**

☐ Married/common law

☐ Divorced

☐ Widowed

☐ Single (never married)

4. Have you (or your spouse) had to make any changes to your employment status in orderto support your child with autism? (e.g. cut back on work hours, resign from your position)

☐ No ☐ Yes

5. Does your child have siblings? Do any of these siblings have a medical condition or disability?

☐ No ☐ Yes How many have a medical condition or disability? _____

6. In what year was your child first diagnosed with an autism spectrum disorder?_____

7. Has your child had any other health problems? Please tick as appropriate

Hearing problems ☐ Speech and Language problems ☐ Balance and Coordination problems ☐ Feeding Problems ☐ Clumsiness ☐

Other: (Specify): _____

8. What is your child's gender? ☐ Male ☐ Female

9. What is your child's date of birth? _____(dd/mm/yyyy)

FAMILY NEEDS/EMOTIONAL CHALLENGES

Family Needs

1. With regard to my child's care, I need:

(Please tick as appropriate more than one box)	Very Important	Important	Slightly Important	Not Important	Met	Partly Met	Unmet
Help from other family members in taking care of my child and dealing with issues positively							
Support in deciding how much to let my child do by himself/herself.							
Support with educational decisions about my child.							
Emotional support from other ASD parents							
Assurance that it is not uncommon to have negative feelings about my child's unusual behaviours.							
Counseling for myself and my spouse (e.g. marital strain)							
Support with developing a social network							
Financial support (e.g. from government)							
Assistance from public centres (K.E.D.D.Y)							

Other: Please described briefly……..

……

……

……

……

……

……

Emotional Challenges

1. **To what extent you find dealing with the following behaviours difficult?**
   (1=strongly disagree, 2=disagree, 3=neither agree nor disagree, 4=agree, 5=strongly agree)

(Please tick as appropriate)	1	2	3	4	5
Deficits in language, communication and social skills (interacting with family and community)					
Behaviours that challenge (odd mannerisms, stereotyped behaviours)					
Deficits in self-help skills (eating, dressing)					
Deficits in motor-skills					
Recreational difficulties					
Strict compliance to routine including excessive ritualistic behaviours					
Other behaviours: Please specify					

2. **Which of these challenges would you say you have faced raising your child? Please tick as many as necessary:**

Bullying ☐ Prejudice ☐ Stereotyping ☐ Public unawareness of condition ☐

Society labeling your child as 'disobedient' or 'ignorant' ☐ No challenges ☐

3. **How did you react to the diagnosis of ASD?**
   (1= never, 2= almost never, 3= sometimes, 4= often, 5= very often)

(Please tick as appropriate)	Yes	No	Don't Know	1	2	3	4	5
Shock								
Terror								
Denial								
Sadness								
Depression								
Frustration								
Irritability								
Confusion								
Impaired concentration								
Decreased self-esteem								
Decreased self-efficacy								
Uncertainty								
Anger								
Guilt								
Loneliness								
Helplessness								
Relief								
Hopeful about my child's future								

4. **What coping strategies do you use to get through situations which may arise at home?**

_____

_____

5. **To what extent has your child in the autism spectrum affected your and your family's life?**

(1= little effect, 2=important effect , 3=Neutral , 4=very important effect , 5= great effect)

(Please tick as appropriate)	1	2	3	4	5
Relations with spouses/partners					
Relationships with relatives					
Social networking					
Arrival of a new child in the family					
Quality of my children's life					
Financial situation of my family					

6. **In one word how would you describe raising your child with ASD?**

_____

SERVICES and RESOURCES AND EDUCATIONAL PROVISION

1. **It is important that:**

(Please tick as appropriate)	Very Important	Important	Slightly Important	Not Important	Met	Partly Met	Unmet
Professionals reach' consensus on the best ways to help my child							
My child's school sets up an individual education plan							
My child is educated in a mainstream school.							
My child is educated in a special vocational school.							
My child is educated in a special needs							

school.							

2. How satisfied are you with the following remedial services?

(Please tick as appropriate)	Not satisfied	Partly Satisfied	Satisfied	Very Satisfied
Social Integration				
Sensory Integration				
Behavioural therapy				
Individual Educational Program(I.E.P.)				
Picture Exchange Communication System(PECS)				
Applied Behavioural Analysis(ABA)				
Structured teaching "TEACCH"				
Social stories				
Symbolic Play				
Speech and Language Therapy				
Occupational Therapy				
Music Therapy				

3. What are the benefits of your child's education provision ?

I've seen improvement in:

(Please tick as appropriate)	Agree	Disagree
Child's cognitive development		
Child's adaptive, emotional and social development (e.g. friendships, social networking)		
My child being accepted by others		
My relationship with my child		
Specify other:		

4. To what extent have services and provision been affected by the austerity measures?

Please circle number as appropriate

1 2 3 4 5

Little effect Great effect

PARENT - PROFESSIONAL INTERACTIONS

1. How would you rate your relationship with the following professionals?

(1= very bad, 2= bad, 3= good, 4= very good, 5= excellent)

(Please tick as appropriate)	1	2	3	4	5	No contact
Special Needs Teacher						
Educational Psychologist						
Speech and Language Therapist						
Occupational Therapist						
Social Worker						
Psychiatrist						
Psysical Therapist						

2. Please answer the following questions about your experiences withexperts (professionals) during your child's diagnosis.

(Please tick as appropriate)	Strongly Disagree	Disagree	Neutral	Strongly Agree	Agree
My child's diagnosis was completed in a timely and professional manner.					
I received clear information on: a) ASD profile and needs (eg. dealing with behaviour challenges);					
b) Suitable educational provision in a special or mainstream school;					
c) Financial entitlements available to my child and family;					
d) Educational resources to educate myself about ASD.					
The professionals: a) Helped me deal with my fears about my child's future;					
b) Showed respect and were discrete;					
c) Answered my questions honestly;					
d) Offered services continuously rather than					

only in times of crisis.					

3. In your opinion, what are the factors that helped or obstructed your workings with professionals?

(Please tick as appropriate)	Yes	No	Don't know
Professionals' time pressures			
Their lack of knowledge and expertise on ASD			
Their limited communication			
Their lack of shared beliefs and values			
Their limited accountability regarding decision making			
Policy and practical constraints due to lack of resources			
My own limited time			
My lack of confidence in dealing with professionals			
My lack of knowledge and understanding of ASD			
Other (please specify):			

4. In my working relationship with professionals, they:

(Please tick as appropriate)	Very Important	Important	Slightly Important	Not Important	Met	Partly Met	Unmet
Provide a welcoming atmosphere							
Value my opinions and decisions regarding treatment and education interventions							
Consider suggestions and give me feedback							
Involve me in my child's treatments and therapies							
Involve me in the individual education plans							
Exchange information with other educational professionals							
Cooperate with my child's special teacher							
Offer me opportunities for parent training in remedial programs (e.g. ABA, TEACCH)							

Thank you for your participation

Would you like to receive a copy of the results of this study?

☐ Yes ☐ No

Appendix 6

QUESTIONNAIRE FOR PROFESSIONALS WHO WORK WITH ASD CHILDREN

Professionals' background

1. Gender (Please tick as appropriate) ☐ Male ☐ Female

2. Working experience:

(Please tick as appropriate)	Yes	No
Less of 10 years		
10 - 15 years		
15 - 20 years		
20 - 25 years		

2a. About your role: _____

3.What is your current profession?

(Please tick as appropriate)	YES		YES
Special Educator		Social Work	
Special Educational Needs Teacher		Psychiatrist	
Physiotherapy		Speech and Language Therapist	
Clinical Psychologist		Autism Therapist	
Educational Psychologist		Occupational Therapist	

4. What area of service provision are you involved in? (Please tick as appropriate)

Mainstream Education ☐ Assessment ☐

Special Needs Education ☐ Multidisciplinary Team of KEDDY ☐

Autism Specific Education ☐ Adult Day Services ☐

Other : Please specify

5. Which age group of students do you work with? Tick all that apply:

0-6 yrs ☐ 7-12yrs 13-18yrs ☐ +18yrs ☐ All Ages ☐

6. What are the most important tasks in your profession when dealing with ASD children ?

(Please tick as appropriate)	Yes	No
Assessment		
Diagnosis		
Counselling		
Providing Individual Educational Program (I.E.P.)		
Teaching		
Meeting the individual needs of ASD children		

Professional Development and Training

1. Have you ever attended autism training?

1a . If yes, what topics did the training cover? (tick all that apply)

- ☐ Introduction to autism
- ☐ Sensory needs
- ☐ Communication
- ☐ Behaviour
- ☐ Other (please specify)

1b. If you selected other, please specify:

2. How many hours did the training seminars last?

(Please tick as appropriate)	Yes	No
10 hours		
10 - 30 hours		
30 - 50 hours		
50+ hours		

3. What type of consultancy support/training do you think or your school/centre could benefit from?

- ☐ Advice about individual student's social and communication needs
- ☐ Auditing of the environment to be more autism-friendly (e.g. designing a classrc sensory room)
- ☐ Adapting policies and procedures(e.g.curriculum design,playtime/break time support) to better support students with autism
- ☐ Tailored workshops on supporting particular students (e.g. transition to adulthoo and secondary school)
- ☐ Working in partnership with families
- ☐ Listening to direct school experiences from those with autism (eg. children, adul
- ☐ Educating ASD children
- ☐ Other (please specify

4. Have you been involved in any of the following ASD Programmes with families?

Applied Behaviour Analysis (ABA) ☐ Structured teaching TEACCH ☐

Other : Please specify

5. Do you feel your training has provided you with the necessary skills to successfully deliver an ASD programme? (Please tick as appropriate)

Always ☐ Sometimes ☐ Never ☐ Don't Know ☐

Parent - Professional Interactions

1. Have you noted parents whether the parents of ASD children experience significant difficulties accessing the following services?

(Please tick as appropriate)	YES		YES
Formal Diagnosis		Medical Services	
Educational Provisions		Occupational Therapy	

Educational funding		Social Worker	
Clinical Psychologist		Psychiatrist	
Educational Psychologist		Speech and Language Therapist	
Special Educational Needs Teacher		Autism Therapist	
Music Therapy		Other:	

2. **Have parents of ASD children been experiencing emotional difficulties dealing with the following behaviours?**

(Please tick as appropriate)	YES		YES
Strict compliance to routine behaviour(e.g. ritualistic)		Lack of social interaction with parents	
Deficits in social and language communication skills		Behaviours that challenge	
Deficits in self-help skills		Deficits in motor skills	
Other behaviours: Please specify			

3. **What is the impact of a child's ASD condition on the parents in terms of ?**

(Please tick as appropriate)	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Education					
Occupational and employment opportunities					
Social and recreational interests					
Social networks					
Family interactions					
Siblings wellbeing					

4. **To what extent are you satisfied with your cooperation with the parents of ASD children?**

Please circle number as appropriate

1 2 3 4 5

Little satisfaction Great satisfaction

Inter-Professional collaboration

1. **How does the school/centre support intercollegiality and collaboration among staff?**

☐ through opportunities to develop good relationships;

- ☐ through encouragement from the senior management team;
- ☐ through existing school policies;
- ☐ by encouraging participation in professional development activities;
- ☐ by organizing out-of-school activities (e.g., camps, visits, country walks);
- ☐ by encouraging informal INSET (e.g. coffee breaks);
- ☐ by approaching collaboration as a long –term school-wide professional development;
- ☐ by sharing expertise

Other (please specify):

2. What are the perceived benefits resulting of staff collaboration?

- ☐ at an individual level (enhancing staff's sense of support, increasing assertiveness, combating the solitary nature of the profession);
- ☐ at a client level (supporting children and their families);
- ☐ at a professional level (classroom management, enhancing professional practice, testing new models of professional development);
- ☐ at an organizational level (enhancing the image of the school, stimulating changes in the organizational structure)

Other (please specify):

3. In your opinion, have you made any sacrifices or had any losses as a result of collaborating with colleagues, in terms of:

- ☐ time commitment and constraints;
- ☐ losing autonomy/independence (e.g., being the expert in your domain);

☐ having your decisions being cross-examined;

☐ feeling the need to compromise;

☐ differentiating between collective and individual contribution;

☐ feelings of having your 'territory' being intruded upon (e.g., not necessarily leading the lesson);

☐ stress and pressure to develop effective channels of communication;

Other (please specify):

4. **In your opinion, to what extent, does compatibility in values and beliefs among staff (e.g., valuing the dignity of ASD children, celebrating diversity in learning styles and development, sharing responsibility) support staff collaboration?**
Please circle number as appropriate

1 2 3 4 5

Little support Great support

5. **Do you think it is important to change to support collaboration, and if so in what ways?**

_____

6. **Do the resources available under the austerity policy affect your work?**

_____

Thank you for your co-operation

Would you like to receive a copy of the results of this study?

☐ Yes ☐ No

Appendix 7

SEMI -STRUCTURED INTERVIEW SCHEDULE FOR PARENTS WITH CHILDREN WITH ASD

Family needs/ Parent's Emotional Challenges and Coping mechanisms

Family needs

1. When did you first become aware of your child's difficulties?
2. What first prompted you to seek professional help?
3. How did you react to your child's diagnosis? What emotions did you feel?
4. How and when did a diagnosis of Autism Spectrum Disorders come about?
5. Describe your experience of the assessment and diagnostic process.
6. What kind of family needs do you have regarding the care of your child with ASD?
7. What are the challenges you experienced in terms of: a) accessing family resourcesb) finding a private or state centre c) identifying relevant professionals?

Emotional Challenges

1. How would you describe the experience of raising a child with autism (in terms of education and wellbeing)?
2. Did you agree to the treatment process for your child?
3. Would you tell me a bit about your child's strengths and differences and what kind of help you need to overcome daily challenges?
4. To what extent do you keep your pain/struggle to cope with everyday challenges to yourself?
5. Do you feel that the problems you have experienced have placed any pressures on you and your family?
6. Do you need parental counselling to help you deal with ASD and/or your mental health and/or marital and/or family interactions?
7. How do you feel your child is treated by others? What kind of problems does your child display when you are out?

8. What kind of emotional challenges do you face in raising your child with ASD?
9. Have you had emotional support from other parents of children with ASD? What kind of external support do you need?
10. What do you think is the most important obstacle in dealing with the challenges posed?
11. In what ways do challenges impact on the siblings?
12. How do you think the family unit has to change as the individual with autism moves from childhood to adulthood ? How do you think your child with ASD will react regarding to the transition from childhood to adulthood?

Financial support, services and resources

1. Do you have any government or private financial assistance for treatment or therapy for your children?
2. How supported do you feel by the local authority with regards to financial support?
3. Do you think that there is a choice of remediation programmes in our country (Greece)?
4. To what extent are you satisfied with the education of your child ?
5. To what extent you think that your child's emotional and social well being has developed could/develop at a mainstream school?
6. To what extent are you satisfied with the quality of the school services that your child has received?
7. Have you seen your child improving academically and socially? What kind of expectations for the future, have you got for your child?
8. What do you think would enhance the treatment options and resources regarding school services/programmes in Greece?
9. Are there adequate resources in schools for children with a disability? Are there any differences that you know of between state special and mainstream schools?

Social Networks

1. What type of social network (extended family, parent organisations/groups, friends/church/other social club) do you find to be supportive of your child's disability?
2. What kind of support do you need to develop a social network for your child?
3. Has your child made friendships with peers?

4. Does your child participate in other activities and do you share these with him? What is his/her afterschool life like?
5. Have you made contact with other families who have children with autism? Have you shared experiences from your daily life with them?
6. Do you find societies such as the Greek Autistic Society useful?
7. Have you experienced social stigmatisation and prejudice?
8. Are your relationships with others difficult?

Coping Mechanisms

1. Have you attended any courses to help you cope with your child on a day to day basis?
2. What challenges have you and your family have experienced in supporting your child in our country in the age of austerity? How has your child affected your life and your family's life?
3. Have you used coping strategies to get through each day? To what extent are they successful/do they help? What kind of coping strategies have you use to address situations that may arise at home (like aggressive behaviour, psychomotor stimulation, tantrums or self-destructive habits)?
4. Does your husband/wife participate in your child's remediation? Do you work together with him?
5. How is your working life affected by having a child with autism, and your relationship with your spouse / partner, and the other members of your family?

Parents perceptions on ASD Support and Provision

1. In what ways have you been supported by school and experts? What systems of support do you believe you need so you can cope effectively?
2. Does the existing education legislation for Special Education Needs (SEN) help your ASD child to receive the appropriate educational support and provision?
3. Does your child attend a special school for autism? What do you believe is the best way to develop your child's potential?
4. Does your child follow an Individual Education Program (IEP)? Did you participate in the planning of it?

5. Have you attended any education and support programmes for parents (e.g. CYGNET)?
6. Are you satisfied withthe remediation services of your child (e.g. PECS, ABA, TEACCH, Social Stories, Behaviour Therapy, Sensory Integration)?
7. Has your child benefited from his/her education provision ? Have you seen improvement in some areas, and if so, which?
8. What kind of services do you receive to support your child with ASD in our resource starved country? Could you please, describe any experiences related to accessing services and support that you think are particularly important?
9. In your opinion, do the experts/professionals accept the proper accountability in helping you face the challenges of your child?
10. Do you feel that the only support/advice you get is from experts?
11. Have the experts replaced other more informal systems of support?
12. What is the role of the state/public services in providing support?
13. What kind of sources of information about autism do you use?
14. Have you ever participated in the remedial programme of your child? Do you consider that your child's remedial programme is appropriate for his/her needs?
15. How do you evaluate the services you have received for your child with ASD? Which factors do you think are necessary to enhance the treatment options and resources regarding school services/programmes in Greece?

Parent -Professional Interactions

1. Do you cooperate constructively with your child's teacher within a welcoming atmosphere? If I were your child's teacher, what advice would you want to give me so that your child has the best possible education?
2. If you were giving advice to a professional who needed to explain to parents that their child has Autism Spectrum Disorders, what would that advice be?
3. In your opinion, what is the most important element in making professional – parent collaboration successful?
4. How would you evaluate your relationship with ASD professionals? Which professional have you had have no contact with?
5. What kind of factors facilitated your cooperation with professionals ? What kind of factors hindered your cooperation with them ?

6. In your opinion, what kind of socioeconomic factors influence your working with the professionals in the age of austerity?
7. In general, what existing collaborative activities would you consider to be examples of good-innovative practice within a school or state centre?
8. Could you please describe your experience of collaborating with professionals? What do you think are the overall challenges faced by professionals and parents in developing collaborative links?

Parental involvement

1. How often do you deal with the learning difficulties of your child? Do you help him/her to overcome difficulties in specific areas (for example; listening to instructions – following rules - social skills)?
2. Are you actively involved in the individual education plans and your child's treatment and education?
3. Do you think your opinions and decisions regarding your child's treatment and educational intervention were valued?
4. What factors affect your parental involvement in the diagnosis and Support of ASD educational support and provision?
5. Do you participate substantially in intervention programmes of your child such as applied behavior analysis, relationship development intervention, sensory integration? If yes, explain your experience.

Additional Comments

1. Do you think there have been any changes in yourself (e.g. behaviour, attitude) as a result of your experiences of raising an ASD child?
2. Is there anything else that you would like to add?

Thank you for your co-operation

Appendix 8

SEMI STRUCTURED INTERVIEW SCHEDULE FOR PROFESSIONALS WHO WORK WITH ASD CHILDREN

Greek Special Educational Laws and Policies

1. Is the current Greek special education law helpful in guiding your work with ASD children?
2. What policy changes could be made that would increase your effectiveness as a professional working with children with ASD? What, if anything, needs to change?
3. What is your opinion about how children with ASD are identified and placed in special education according to Greek SEN law?

Professionals' Perceptions on ASD Support and Provision

1. What do you think is your role in ensuring that the available programme/curriculum meets the needs of children with ASD?
2. What do you think are the goals of education for these children and can they be achieved in an inclusive school?
3. How much support for children with ASD do you offer in the age of austerity?
4. Do you have sufficient resources to support these children?
5. What do you think of the provision of disability services to children with ASD?
6. What type of curriculum do you feel could appropriately meet the needs of children with ASD?
7. Have you ever been personally involved in the delivery of ASD specific programmes for families?
8. How do the resources in austerity policy affect your work on disability support?

Professionals' Challenges and Development

1. What motivated you to work in the area of SEN/ASD?
2. What are the greatest challenges you face as a professional, in particular working with children with ASD?

3. Do you experience stress when dealing with these children and how do you cope with it?
4. What is your understanding of how the disability support currently operates? What kind of issues of disability has austerity brought to the fore?
5. What is your opinion about how the progress of children with ASD is evaluated and communicated among the various stakeholders, including parents?
6. Do you feel that your training for working with children with ASD is sufficient and you have any specialist knowledge with regard to these children?
7. Has your professional capability been affected by the economical crisis? In what kind of areas?
8. What types of support/professional development do you need to meet these challenges and what is the best way for you to access this support/professional development?
9. What in-service/professional development programmes/courses are you aware of in the area of ASD support?
10. What (further) professional development do you think you need to carry out your roles and responsibilities as a professional?

Inter-Professional Collaboration

1. How do you collaborate with other educators or professionals? Do you offer and/or accept feedback from other professionals?
2. What do you think facilitates or hinders inter-professional collaboration? What
3. are the factors that affect your professional relationship with other professionals?
4. Do you find appropriate ways to collaborate with other professionals that are effective for promoting good individual and family outcomes?
5. What is a neglected area in inter-professional collaboration in the age of austerity?
6. Do you think there are any important changes that can be made to improve the collaborative practices of professionals?
7. In general, what existing collaborative activities would you consider to be
8. Examples of good/innovative practice within the school/centre?
9. What do you think are the overall future challenges faced by staff in developing collaborative links among staff members and others outside the school/centre?

Parent - Professional Interactions

1. How do you collaborate or interact with the parents of children with ASD? Have you built a good relationship with them?
2. Are there any neglected areas in your collaboration with the parents of these children?

3. What are the factors that affect your collaboration with parents? What are the factors that help or hinder you working with parents?
4. Do you find any difficulty in your communication with parents?
5. Some parents have problems accessing the community, can you do about that? Can you support these parents in this regard?
6. How can the relationships between parents and professionals be improved? How important is it for parents to experience honest and open communication with you?
7. In what ways and to what extent can a professional meet parents' expectations influence their trust?
8. Have you identified any practical problems during your interaction with the parents of children with ASD?
9. In your experience, have you whether noted the parents of these children experience significant distress or difficulty accessing the special needs services?

Additional Comments

1. Do you think any changes have affected you and/or work as a result of your experiences of participating in ASD children's education and well-being?
2. Is there anything else that you would like to add?

Thank you for your co-operation

Appendix 9

PARENT INTERVIEW TRANSCRIPT (translated from Greek)

1. What kind of challenges did you face concerning: a) finding private or state sector b) the finding of appropriate professionals?

   Firstly, there were only a few professionals and I couldn't find any specialist staff. Many of them exploited us and treated us badly. Gradually I started realizing the real professionals and the specialists were in Autism. We realized that something goes wrong very early. My mother was a dentist and she understood that it was Autism. When he was 1 year old, we could see some indications and we visited a psycho-pedagogical centre in Nea Ionia and then another one. They gave us the same diagnosis. He had the all the characteristics that an autistic child has. They examined him and he looked at the wall.

2. How did you react after your child's diagnosis? How did you feel? Did you deal with it on your own? Did you share it with other people? Did your immediate family support you?

   At the beginning, I reacted very badly. During the first semester we saw different specialists who disappointed us, giving him a prognosis. They told us that he should spend his whole life in an institution. Some people suggested sending him to an institution so as not to bond with him. Some of my friends didn't want him around because he was very naughty. A few people supported me. My mother was one of them. When I was at work, my mum took care of him.

3. What kind of needs did you have for your child's care?

   When he was in a nursery school, he also took part in some therapies. The people there disappointed us. Up to the age of three, he got worse and I was reduced to resigning from work. My mother gave us some money so we found a teacher from the U.S.A., and she was well informed about autism. Over the course of a year, we saw the first signs of development. After that, we tried to enrol him in a state nursery, but he wasn't accepted so we enrolled him in a private nursery with a teacher assistant.

4. What was your role concerning your child's needs?

I took things in hand from the beginning. His father couldn't deal with it. I searched for his teachers and I was responsible for every decision.

5. Can you describe your experience concerning your child's assessment and the diagnostic procedure?

   The specialists didn't help us. They gave us only theoretical advice. They didn't help us in the practical issues of everyday life. There were some parents who helped us a lot and we became friends. We had the same problem and that brought us close. The advice we took from the Centres for Differential Diagnosis and Support of Special Educational Needs (K.E.D.D.Y.) didn't help us at all. We had a problem with the diapers but nobody told us to stop using them.

6. What kind of emotional challenges did you face during your child's upbringing? What was the most important handicap you had to overcome?

   He was very young. The whole family's life was affected by this situation. We had a really hard time. We went on holiday when he grew up. We used to go for a walk but we had to go back because he would becomes very nervous. His brother started complaining because we adapted our life to his needs. My older child's life changed because he learned to take care of him from an early age. We have experienced strange feelings all these years. We took many difficult decisions on our own.

7. To what extent did you keep your struggle private in order to face the everyday challenges?

   The people couldn't understand us because they didn't have the same experience. Some of them were really afraid when they heard that we had an autistic child. Even his teacher was afraid of him. She didn't talk to him.

8. How do other people treat your child? What kind of problems does he have when you are not at home? Have you experienced social bias?

   Over time, the people became used to us. Our friends and the school got used to it. They are not afraid of him anymore. They realize that he is different but they accept and like him. Some of my friends still don't want him. There is a stigma attached to our family. My brother still hasn't accepted him.
9. Is there anyone else who offers emotional care to your child apart from you?

   We have created a good relationship with many people. My child feels better too, so I believe that we live a normal life now.

10. As a parent with an autistic child, do you feel that the problems you face put pressure on you and your family?

    It was very tiring for all of us. My husband couldn't manage it. During the first few years, he dealt with a lot of issues because I had to stay at home with my child. I was strong enough to spend a lot of time with my child.

11. Did you get any emotional support from other parents with autistic children? If so, what kind of support?

    I met some parents while attending a program who gave me useful information. We became friends with some of them because they didn't find my son's attitude strange. We felt comfortable in their houses.

12. Does the municipality offer you financial support for your child's treatment?

    We receive a state benefit for our child's disability.

13. What factors are necessary, do you think, to reinforce the treatments and the services in schools?

    The school offers a teacher assistant and that is very helpful. The state should check that the teacher assistant is suitable for the child. The relationship between the therapist and the child must be good. Unfortunately, in public (state) schools there is no flexibility. Our children are assessed by people who are not the appropriate ones for our children. Therapists sometimes ask our children questions that make them feel uncomfortable and they don't want to cooperate.

14. Are you satisfied with your child's education? Have you noticed any progress in your child's academic and social skills?

    We have had the same teacher assistant for many years and that helps him a lot. The teachers can notice it too. His progress came after years but I am very satisfied with my child's progress. School helped him a lot. Everyone has accepted him. He learned to read, calculate and help himself.

15. What expectations do you have for your child's future? Do you feel anxious about his future? What kind of thoughts do you have?

    I am worried whether his progress is enough to give him the opportunity to line alone. I am worried about whether he can be independent one day. We are always afraid of new problems. If new problems appear, they may stop his progress.

16. What kind of social network do you need in order to support your child's particular situation?

    The school should be better organized. Nowadays I see some changes. I attend some seminars with other parents where psychologists give useful advice and support us. Definitely, all these clubs offer a lot of help. Our club gave us a lot of interesting brochures and I met new people there.

17. What strategies did you use to cope in your everyday life (with. aggressive attitude, anger, self-defeating attitude etc.) ? Were they successful or not?

    I didn't follow a specific strategy. Till the age of five we had to be patient. Over the years he became a very quiet boy We tried to find our own ways to help him.

18. Do you think that you are victims of this situation in our country? Do you want to or can you carry this emotional baggage on your own?

    Nobody offered us help for the future. There are no organizations that can look after my child if something bad happens to us. We have to ensure his future. The state doesn't care about these children. I am worried about our future and this problem is unsolved. I hope he will be in dependent one day.

19. Does the legislature for special education help your child receive the appropriate educational benefits and services? Has the financial crisis spotlighted anything in particular?

    All kinds of disabilities need money. The less money the state spends, the worse things are with our families. New experiences need money. The state should offer a teacher assistant from the beginning of the school year without asking for money from us. On the other hand, I feel grateful because the state gave me the opportunity to have a teacher assistant for my child. Everything went right for my child's education.

20. According to you, are the therapists responsible enough to address your child's challenges? Do they have specific knowledge?

    They are not all qualified. You need to search a lot before you find a good therapist. We met some therapists who were dangerous for my child's progress. On the other hand, we found people who helped him significantly.

21. Do you think that the professionals can replace other unofficial organizations, such as social clubs in our country?

Definitely not. I am also a teacher and I can see the specialists from both the parents' and the teachers; points of view. I know that many specialists are note sensitive enough to help these children. That may be because they change school every year.

22. Are you satisfied with the programmes your child has followed during school years?

I am quite satisfied. People who look for the appropriate programme can only have positive results. There have been a lot of mistakes in his education but I try to forget about them because I can see the progress in his life.

23. What is the most important thing for making successful cooperation between parents and specialists?

Flexibility and adapting to the parent's needs can foster collaboration. Specialists must be optimistic. I didn't have useful collaboration with pessimistic specialists. We always need hope in order to be able to help our children. The specialists must adapt to the parents' needs. Specialists must understand parents.

24. How was your relationship with the professionals? Was there a professional that you didn't have any contact with at all?

I cannot distinguish between the specialists. I didn't get on well with a psychologist or a speech therapist. Good collaboration doesn't have to do with the specialist's knowledge. It is a matter of their character.

25. According to you, what kind of socio-economic factors have affected your collaboration with specialists during the cuts in social budget? A)What factors facilitated your collaboration with the professionals? B). What factors inhibited your collaboration with the professionals?

Economic factors can affect collaboration a lot. Furthermore, as a teacher myself, I could cooperate with the professionals more easily than other parents who don't work with children. I could follow their suggestions easily.

Have you ever been involved in your child's therapeutic programme?

26. Do the professionals take into account your opinion and your decisions concerning your child's treatment?

Yes, of course. In the beginning, I studied a lot. I teach computer science at school so I used my computer a lot. I offered my help in the program. Some specialists asked for my help so I used to prepare my work and give it to them.

27. What are the factors that affect parental involvement in the diagnosis and the services which are offered for autism support?

The specialists wanted me to be involved in the whole procedure. They asked me to be. Due to the fact that I couldn't afford to pay all these specialists, I contributed to his education the rest of the time. The specialists directed me on how to do that. It was impossible for the specialists to achieve their goals with one session. I put his daily programme into practice.

28. Were there any changes in yourself as a result of your experience of raising an autistic child?

Yes, I changed a lot. I also changed as a teacher. In the beginning, I blamed my students for not succeeding at school subjects. Then I realized that there are other things that prevent them from being excellent students at school. Now I see my students in a totally different way.

29. Tell me one of your wishes concerning improvement to the services that are offered to autistic children in Greece.

The state must constantly vet the educational procedures. If I was not a good mother, I could neglect my child. The state doesn't know that. The state doesn't care if I have the ability to help my child because there is no supervision. We should have some supervisors to check the children's progress. If that happened, parents would feel less stress about their children's future.

Thank you very much.

Appendix 10

PROFESSIONAL INTERVIEW (translated).

1. Thank you for taking part in this interview in relation to my research. I would like to ask you if you believe that the present Greek state legislature in special education guides your work with autistic children. I mean, if it helps you, at least in part, to support these children.

   I can't say that it helps us, but it definitely gives us a direction and a narrow context because our field is evaluation and diagnosis so it helps us in those areas. It also organizes our work. We are all forced to follow the same principles and have the same rules. Even if we disagree with some parts of the law, we still know what the available choices are.

2. Which changes could be made in educational policy to improve the effectiveness of these children's support – if you think changes are necessary?.

   I'm not sure if hiring new staff is included in it, but it is obvious that having more staff, more services like this, and permanent teams of employees, is really important. When you have to collaborate with new people every year, you can't offer substantive support. It would also be very useful to put these services in each school so that every team could support a stable number of students. That's all, I think.

3. Generally, according to the Greek educational legislation, do you believe that these children gain in the environment of the school? Are there any special services that support them while they are at school?

   Let's say that the institution of assistant teachers is something like that. We support these children with the assistant teacher's help, but we don't regard these children as children with special needs. The law hasn't made provision for these children so there isn't any availability for these children to have a different programme or have fewer hours at school. For example, during the exam period, we treat these children like the rest of the children at school. That is a significant problem, I think.

4. What should be your role in order to assure an appropriate educational intervention for these children? Do you believe that your current role is appropriate and offer the best support to these children? Is there anything that should change or something that could be add to flesh your role out?

If there were more employees in our field, we could develop a better relationship with the children; we could also supervise the children more regularly, and we could advise their parents. Having more staff would give us the opportunity to give advice to the teachers, and create a special program for these children, to observe them in a better way. One of our biggest problems is that we are not able to have well-rounded supervision of these children.

5. Do you believe that the educational goals you and the teachers at school aim for are achievable in the school environment?

I think that some of them are, especially those for highly functional children. On the other hand, these goals do not help low functioning children. General schools cannot accomplish their goals because there are a lot of children in the classroom, the teachers are not qualified, and there is lack of supervision. The teachers' and the rest of the parents' understanding is non-existent, so we are not able to achieve our goals.

6. How are children with autism supported during the social budget cuts? Do you believe that this situation influences these children's support and the way you work?

Of course it does. Due to bad financial conditions, children are not able to attend sessions. Their parents cannot afford an assistant teacher at school and the state doesn't offer support at school. Assistant teachers are rare in schools. Parents do not have the money to turn to specialists for help. It is also a big issue that our effectiveness is reduced because we do not have the appropriate equipment, and we do not have the ability to attend educational seminars.

7. Do you devise a special program that helps the children with autism and their teachers at schools?

Due to the fact that we are not able to meet these children and their parents frequently, we cannot follow a special program. The children who have an assistant teacher at school follow a special program because there is always an expert with them. There are children with autism who do not have an assistant teacher at school because the state hasn't approved it. These children face a lot of difficulties.

8. Do you sometimes follow the guiding principles of the curriculum of Institute of Educational Policy (IEP)?Do you think that it is appropriate or it needs some changes?

In the primary school, we follow the curriculum and the syllabus concerning basic subjects such as the Greek language and maths because each personalized program includes not only special techniques but the syllabus, too. The difference is that we approach the syllabus in a different way. In the kindergarten, we do not follow the curriculum because it is not adequate.

9. Have you ever taken part in carrying some special programs for autistic children personally?

No, I haven't.

10. What motivated you to work in the field of special education?

It was purely accidental.

11. What have been the biggest challenges you have faced as a professional since you started working with autistic children? Something that impressed you a lot?

It was the children's skills for sure. The difference you notice in the child's development every time you meet her. At the beginning of my career, I didn't expect to see any changes. The children become attached to the people at the Centres for Differential Diagnosis and Support of Special Education Needs (K.E.D.D.Y.). I didn't expect to see that as well. My colleagues and I have become more optimistic since then, thanks to the children's progress.

12. Do you feel that your education is sufficient for you to help autistic children?

No, it's not.

13. What would you like to happen in order to feel like a complete professional and take more responsibility for these children? What extra education would you like to have?

Firstly, I think that there should be continuous re-education/in-service training for teachers, especially those who work in the kindergarten. We should be able to put our knowledge into practice. Now, we do not have the opportunity to use our knowledge and that's the reason I think we are inadequate. On the one hand, we have a lot of experience because we see a lot of children, but on the other hand, we do not know if we make mistakes because there aren't any supervisors to audit us. Furthermore, we don't know if our suggestions are practical because we get no feedback from schools.

14. What kind of issues have come to the fore due to austerity? How do you understand the support for disability, including the autism spectrum disorder?

    Due to austerity, we do not have the ability to have sessions, specialists and generally, enough staff to work with disabled children. We also do not have the funding to support these children with a child psychiatrist or other doctors. Families also have a lot of difficulties because there are a lot of parents who are unemployed and can't afford private therapies. On the other hand, there are families where the parents work many hours a day and they do not have enough free time to spend with their children. I believe that these are very important issues.

15. Are you nervous or stressed when you collaborate with these children? How do you cope?

    Of course! I think that the multidisciplinary team helps a lot, in this case. These children have many differences, so we are never sure what exactly to do for them. Teamwork is necessary.

16. I suppose you must be aware of some educational programs for autism. I would like to ask you if you have ever been trained in supportive programs such as 'TEACCH' or 'PECS' or something else.

    I have been trained in 'PECS' and in 'TEACCH,' a little. I do not regard the rest as educational programs. They have an informative character. All these are not included in the service where we work.

17. Have your professional skills been influenced by the current financial crisis?

    I think that the stress we feel in our everyday lives affects everybody. The fact that there isn't enough material available and that there is lack of on the job education affects our professional skills too.

18. How do you collaborate with the other teachers and the other specialists? Do you compare notes? Do you accept feedback? Generally, do you have good collaboration?

    Most times our collaboration is really good, and that helps us a lot.

19. Which are the factors that help or prevent your collaboration with the other professionals?

A limiting factor is that some professionals are unapproachable and they do not want to communicate with other people due to lack of self-confidence. A negative attitude towards work affects collaboration with the others too. On the other hand, common concerns, t in a positive way, support collaboration between us.

20. What are the benefits of collaboration between the staff?
Collaboration helps us find quicker solutions and make better diagnoses. It also helps us brainstorm regarding our goals.

21. How can you cooperate and interact with parents who have autistic children? \

22. Is communication with them difficult?

Due to the fact that we work in the kindergarten, we are the first to get contact with these parents. The communication between the parents and us is difficult because they either haven't realized or they haven't accepted their child's problem yet. In the kindergarten, the children do not show big differences, so they find it difficult to accept our suggestions. They believe that their children have more ability than they actually have.

23. What should be done to improve your cooperation with these parents? What should change?

I think that if our service was in schools, our relations with the parents would be much better. I think that they do not trust us because we are a public sector. If we had the opportunity to work in the school, we would be able to meet them more often. The first time they come to our service, they are a little bit hesitant, the second time they are negative, the third time they seem to be more receptive. Even when they visit us the following year, our relations are better because they feel more comfortable.

24. What are the factors which help and the factors which prevent your cooperation with these parents? What helps you improve your work?

An important factor that hinders our work is the time we have to spend on each case. Another factor is the bad conditions we have to overcome. For example, there aren't enough chairs or a lot of meeting rooms in our buildings. Sometimes we can't give them solutions or we give solutions that are not acceptable to them. When we suggest they find a special school, they really do not like this solution because we all know that the conditions in these schools are not good. If we had the chance to supervise them more often, they would feel better because they would be able to note their children's progress.

25. Is it important for you to have open communication with parents?

    Yes, it is very important.

26. Have you ever faced any practical problems while interacting with parents?

    Sometimes language is a big issue. Some parents don't speak Greek or it is difficult for them to understand us. There are parents who speak only English and they haven't realized what happens to their children.

27. According to your experience, do you believe that parents find it difficult to access the services?

    Yes, I do. It depends on their financial resources. Parents, who are badly off, have difficulty in having access. Maybe their education plays an important role too. Parents, who are not well educated, do not know where to go. If we had the opportunity to accompany them, it would be very helpful.

28. Do you think that parents face social bias?

    Yes, social bias exists at school and with the other families.

29. How do you help them?

    We sometimes direct them to services that can help them, such as associations of parents with autistic children or disabled children. We rarely go to schools in order to talk to the teachers and parents. These activities would give us the opportunity to become sensitized to the school environment.

30. Have you realized any changes in yourself since you started working with autistic children?

    When I started working with autistic children, I started seeing all children in a new light. I realized that each child is different, with different abilities and skills. I also realized the importance of social skills for every child.

31. In conclusion, I would like to thank you and I would also like you to tell me one of your wishes or your expectations for the future. What could be done in Greece in order to offer better services to these kids?

There should be supervision by a regulator in order to have a stable programme. Professionals and parents need to follow a common policy in order to feel more secure.

Thank you very much.